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ABSTRACT

Symposium papers describe programs which use volunteers to provide rehabilitation technology services. George Winston describes Australia's Technical Aid to the Disabled (TAD), focusing on volunteer recruitment and selection, legal liability, volunteer insurance, advantages and limitations of the volunteer approach, and the TAD organization, including case examples. Daniel Barak's paper, titled "Disability Must Not Necessarily Handicap Daily Life--MILBAT in Israel" describes an information center where disabled individuals can try out assistive aids. MILBAT's founding and plans for the future are discussed, and a flowchart is provided of the searching process for the right solution. "REMAP of Great Britain: A Voluntary Technical Aids Service," by P. H. Hammond, describes the need for REMAP (Rehabilitation Engineering Movement Advisory Panels) and its operating structure involving 90 panels of volunteers. Appended to the paper is a report by Jim Tobias which outlines the history of REMAP and the environment of health care and rehabilitation within which REMAP operates. Comments from three United States observers are presented, including Helga Roth, Andrea Solarz, and Carole Wayne Forsythe, who describes the function of Volunteers for Medical Engineering. The appendix contains an edited version of the discussion that followed presentation of the papers at the two-part symposium, sponsored by a special interest group of the International Conference of the Association for the Advancement of Rehabilitation Technology (RESNA/ICAART). (JDD)

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VOLUNTEER REHABILITATION TECHNOLOGY:

International Perspectives and Possibilities

Edited by:
Jim Tobias
Diane E. Woods

Rehabilitation International

Co-Published by:
World Institute on Disability
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Preface and Acknowledgements

Three U.S. based international organizations are working together for the next three years to substantially increase worldwide exchange of expertise, research and information on disability issues and programs. The U.S. Department of Education's National Institute on Disability and Rehabilitation Research awarded two grants in 1987 to support this objective: one to the World Rehabilitation Fund which has been carrying out similar projects for nine years; and the other to the World Institute on Disability in collaboration with Rehabilitation International. The World Institute, based in Berkeley, California, and the World Rehabilitation Fund based in New York, are collaborating on planning and implementing some activities to maximize the impact of the two projects.

The two projects' objectives are:

- To provide U.S. disability experts the opportunity to undertake study-visits in other countries to observe innovative research projects, exemplary programs or policy implementation;
- To disseminate findings and information on key developments and new ideas in other countries in a variety of formats;
- To create an active international network and facilitate ongoing communication in this field between the United States and other countries; and
- To increase the collaboration of the disabled community with researchers, program managers and policy makers

The main activities of the two projects include: funding of U.S. disability specialists and others interested in disability issues to undertake study-visits in other countries for first-hand experience in exemplary practices; dissemination of findings from other countries in a variety of formats; organization of workshops on international experiences in association with major relevant U.S. conferences; and arranging for disability specialists from abroad to meet with U.S. counterparts.

This monograph on Volunteer Rehabilitation Technology represents a collaborative effort among the three organizations along with Jim Tobias as the coordinator/co-editor.

In 1986 Alexandria Enders of the Electronics Industries Foundation (EIF) told us that the U.S. should be doing more to understand the pros and cons of volunteer rehabilitation technology. Next, Jim Tobias applied for and was awarded a fellowship under the World Rehabilitation Fund's International Exchange of Experts and Information in Rehabilitation. He looked at what England was doing with REMAP and in the process got to know Percy Hammond, a Regional organizer of REMAP. Subsequently, it was decided to do a monograph about the three best-known volunteer rehabilitation technology programs. George Winston, chair of Australia's T.A.D. and Danny Barak, founder of Israel's MILBAT, as well as Percy Hammond all agreed to write up their experiences so that we could share them with U.S. audiences.

Then the next step was to arrange a "gathering" to which we could invite "interested parties" from the U.S. and Canada to engage in a dialogue with the chaps from England, Australia and Israel. RESNA/ICAART 1988 was the venue. Included in the appendix of this monograph is an edited, boiled-*down version of the taped transcripts of respondents to the foreign presenters and the discussion tht followed. Don't overlook this. It contains many wonderful expressions of involvement as well as recommendations for the future.

We are indeed grateful to all of those who participated in the symposia, as well as those individuals who agreed to prepare articles for the monograph and responses for the symposia. Those people in particular whom we would like to thank are Alexandra Enders and Ken Reebs of EIF; Colin McLaurin of the University of Virginia; Dudley Childress of the Rehabilitation Institute of Chicago; Carole Wayne Forsythe of VME; Vic Ransom of the Telephone Pioneers; Ralph Hotchkiss, Steve Tremblay of ALPHA ONE; and Martin Marshall (the founder of REMAP).

Helga Roth was unable to come to the meeting, but as someone very knowledgeable about information systems and the National Institute of Disability and Rehabilitation Research (NIDRR), she reviewed the material and prepared remarks for this monograph for which we are grateful.

Ellen Liberti, the NIDRR Project Officer for both the W.I.D. project and the WRF project is to be acknowledged for her support and encouragement.

And we are indebted to those enthusiastic, energetic, creative chaps: Percy Hammond, George Winston and Danny Barak for coming to Montreal and sharing their experiences with us in writing and in person.

As Carol Wayne Forsythe points out: an international collegial network of persons concerned with volunteer rehabilitation technology is now taking shape. Will you join us?

Jim Tobias and Diane Woods, Co-editors
August 1988

AUSTRALIA

THE TECHNICAL AID TO THE DISABLED (TAD) ORGANIZATION

George Winston, Executive Engineer

VOLUNTEERS IN REHABILITATION ENGINEERING

Abstract

With the support of experienced rehabilitation professionals, technical volunteers can be very effective in helping people with disabilities to improve their quality of life by designing and constructing equipment to suit individual needs. The work of technical volunteers complements the effort of rehabilitation engineering services and includes tasks not normally undertaken by such services. The volunteer enjoys exercising his technical creativity and derives deep satisfaction from helping others achieve their life goals. Necessary for the formation of a voluntary group is a pool of engineers and other technical people who have time and resources to build equipment on a voluntary basis. Such a pool exists in Australia and has made it possible for the Technical Aid to the Disabled (TAD) organisation to flourish.

Why Volunteers?

Few societies provide enough resources to cover all the needs of disabled people. Australia certainly cannot claim to be one of these and many services have to be provided by voluntary agencies. There are very few rehabilitation engineering centres and those which exist are very small. Some cities have none at all. Consequently, there are many needs which can only be catered for by voluntary agencies.

It was to fill this gap that TAD organisations were established.

The author believes that conditions favourable to the establishment of such groups exist in other countries, at least those which are industrialised and possibly others as well.

Who Are Effective Volunteers?

The most effective technical volunteers are people with:

—an ability to listen and understand.

—problem solving and conceptual skills.
—good workshop skills and facilities.
—ability to design and construct equipment of a high standard.
—a car.

Mechanical engineers and certain technicians and craftsmen form the core of the volunteer corps. Industrial designers can be very good but often lack workshop skills and facilities. However, almost any technical person with the right skills and attitudes can be a successful volunteer. Dentists, jewellers and upholsterers have made valuable contributions.

What Can Volunteers Achieve?

A volunteer can help a person with a disability to improve his/her quality of life by providing the right equipment or technology. Very often, the solution is simple, low-technology: a means of entering a car unaided or an accessory which allows a quadriplegic to use a computer keyboard. The secret is very careful questioning and listening to the client and a strong desire to respond to the client's need quickly and in the simplest possible way.

Often, the final result is impressive: a person is enabled to function at school, at home or in a workplace.

It is a mistake to underestimate the work of volunteers because they do not form part of a permanent, sophisticated establishment such as a rehabilitation engineering centre whose members are involved in teaching and research. The results of volunteers' work can be not only very functional but visually pleasing and satisfying to use.

Why Do Volunteers Participate?

Technical volunteers are motivated by the desire to help others and by the urge to exercise their ingenuity, creativity and skill.

The greatest reward to the volunteer is the success of the project, i.e. the benefits which the client derives.

It is, however, also important to give volunteers recognition, by publishing results of successful projects and ensuring that they get "feedback" from clients and go-between people such as therapists and teachers, who participate in problem solving teams. Failing this, recognition must come from the volunteer coordinator or committee.

Volunteer Recruitment and Selection

Volunteer recruitment can be effected through:
—professional associations
—technical and trade press
—posters in public places
—articles in local newspapers
—public talks
—community radio announcements

The first three means have been the most effective in Australia. The most helpful organisation has been the Institution of Engineers, Australia.

Volunteer selection is crucial. It is most important to accept only those volunteers who have the attributes listed above.

There are obvious dangers in giving a project to a volunteer who has insufficient skills, is not aware of potential hazards or is not sensitive to the needs of the client.

It is advisable to ask the prospective volunteer to fill in a comprehensive form and submit it, prior to an exhaustive interview with experienced members of the organisation who have good interviewing skills. The success of the whole organisation depends on the care and skill exercised at this point.

What is Needed for Volunteers to Function Well

Most volunteers will have had extensive industrial experience but little or no experience with disabled people or rehabilitation. A new volunteer must feel that he has competent people to refer to, people who understand the need of the disabled person and will guide him in his approach to the problem. He needs information on the disability and its implications, the prognosis, past solutions to similar problems and any pitfalls to be guarded against. Some of this information may be provided by the client or rehabilitation professional but much has to be supplied by coordinating staff of the voluntary organisation or, at least, an experienced volunteer coordinator.

The volunteer must also be confident in his belief that he is responding to a real need which has been thoroughly investigated and that the client is committed to the project. There is great disappointment for a volunteer who has done his best to see his product lying dusty and obviously unused, in a corner.

It is important to prepare written guidelines for volunteers—outlining the procedures and factors such as relationship with the client, the role of the coordinator, reimbursement of material costs, insurance, etc.

A well organised information resource is most helpful to technical volunteers. It provides information on relevant technology and previous solutions as well as background information on disabilities, applications of technology and sources of materials and services.

Volunteers need to know what is happening within the organisation—some kind of newsletter is essential for this purpose.

Some volunteers also appreciate social contact with their peers—occasional gatherings help to maintain the group's cohesion.

Responsibility For Safety

Certain types of projects involve potential hazards of injury to the user, an attendant or a bystander. Obvious sources of hazards are hoists, electrical appliances and moving machinery.

Even though the volunteer is not paid for his services, he is morally and legally obliged to take all possible precautions to protect the user and the public from injury. Legislation varies even within Australia but, in general, lifting and electrical appliances are regulated by legislation and need approval by statutory authorities or, at the very least, they must conform to design codes.

It is almost impossible to impose on volunteers the kind of tight control which is exercised in industry. To do so would mean checking designs before production and inspecting and testing the completed equipment or installation. With a sizeable project load, the amount of time required would be prohibitive. In the event, a reasonable practice is to exercise great care in project allocation, to ensure that projects involving hazards are only offered to very competent and experienced professional or licenced workers. The coordinator should alert the volunteer to the hazard involved.

Small, remote groups of volunteers operating under less than ideally qualified coordinators are particularly vulnerable—risk situations may be created because of insufficient awareness of the hazard.

Legal Liability

Because this section deals with the situation under Australian law, it is not directly applicable in other countries but it will give the reader some guidance as to the various factors to be considered.

The main source of liability is negligence in the design or construction of equipment.

Where there is any possibility of a client being medically damaged by the aid, the appropriate health professional must be involved in the design. This would be true, for example, for all postural and mobility aids for children.

Under Australian law, both TAD and the volunteer may be held liable because the volunteer may be seen as the (gratuitous) agent of the organisation.

There is no liability upon TAD or the volunteer for the misuse of the equipment but both may be liable for failing to specify the correct use of it.

This kind of liability exists whether there is any payment for the equipment or not. It does not depend on any contract, explicit or not, between the organisation and the client.

It is therefore very important for the volunteer or the organisation to specify the correct use of the equipment, e.g. in the form of operating instructions. The instructions should include clear warnings against incorrect uses. This practice reduces the range of malfunctions for which the organisation may be held responsible.

The developmental nature of TAD's kind of voluntary work is that it is often experimental and therefore its success cannot be guaranteed although the organisation and the volunteer will, hopefully, take every precaution against malfunction. Legal opinion is that, inspite of this difference from a

commercial operation, the product must be "reasonably fit for the client's purpose and of merchantable quality, i.e., not defective in any way, having regard to its purpose." This is a contractual liability which exists where the client makes a payment for the service even if it is merely reimbursement for materials.

Many disabled people, if made aware of the unfairness of these expectations, would, I am sure, be prepared to waive their rights to damages as above and would happily accept a reasonable degree of risk. It is, however, not possible under Australian law to contract out of the above legal requirements.

In addition to the above, liability may be created by giving negligent advice, either by a volunteer in person or through the organisation's Journal. Liability for negligent misstatement will arise when the author or the publisher holds himself out as possessing special skill and knowledge on which the reader is likely to act or rely. Legal opinion is that in some cases liability may be limited by the inclusion in the article of a disclaimer statement such as:

"TAD does not guarantee the accuracy of any of the technical information provided in this article (or Journal) and cannot accept any liability, etc."

Such a statement does not inspire confidence and a conscious decision was taken to omit it from the TAD Journal.

The question of professional negligence does not arise if an aid is built by a non-professional. However the volunteer must still exercise due care—sometimes this means getting an engineer to design the aid.

A professional engineer must be involved where people or heavy objects are being lifted more than 2 feet. Vehicle modifications and electrical work using voltages over 32v must be undertaken by licenced tradesmen and are subject to approval by statutory authorities. In general, TAD avoids such work and refers it to qualified full time contractors.

Drawings done by volunteer engineers or architects of structures to be built by others should carry the statement "must be erected by a licenced builder" in order to exempt the organisation from liability for the poor workmanship of an unknown or unrelated contractor. It is desirable to compile a list of reliable, honest and competent contractors who can be recommended where appropriate.

Volunteer Insurance

It is important to insure volunteers against:

—professional indemnity, otherwise called professional negligence.

—personal accident.

—public liability.

The professional indemnity policy covers the organisation, its employees, and volunteers against damages outlined above. The insurer undertakes to pay all sums (within the limits of the policy) which the assured becomes liable to pay for such damages.

Because TAD has,(fortunately) never had a need to claim under this policy, it remains untested. The limit of indemnity is $1,000,000 with a $250 excess. Although the insurer is an Australian company, it has re-insured with Lloyds of London so that the whole risk is carried offshore. Only one Australian insurance company issues this kind of policy. It is still not absolutely clear whether non-professional volunteers are covered by this policy against negligence.

The 1987 premium for this policy was $2400.

The personal accident policy covers volunteers between the ages of 18 and 70 years whilst engaged in voluntary work (including office work). It has not been possible to find cover for older volunteers of whom there is quite a number in TAD. The policy promises to pay compensation for bodily injury or death. The premium is $100 for a cover of $10,000.

The public liability policy covers the organisation, its employees and volunteers against accidental damage to the property of other parties resulting from the work of employees or volunteers. It also has an endorsement covering damages resulting from the sale of goods. The premium is $100 for a cover of $1,000,000.

Paid or Voluntary Coordinator

The coordinator of a group of technical volunteers must be a person with a special set of attributes.

He should be an experienced technical professional such as an engineer or industrial designer. His ability, maturity and experience must inspire the volunteers' confidence. He needs good listening and interviewing skills, to assess the problems presented to him and also to evaluate prospective volunteers. He must also be able to assimilate, quite quickly, knowledge of disabilities and the rehabilitation system.

In addition, he must be able to work harmoniously with the various professionals involved: occupational therapists, physiotherapists, speech pathologists, teachers, nurses, doctors, etc.

On the technical side, he should have experience in mechanical engineering practice and be familiar with prevention of injury from hoists, moving machinery and electric shock.

In the author's experience, a voluntary coordinator can cope with a group of up to 50 or 60 volunteers at most. Beyond this, the workload becomes too high for an unpaid person.

The main problems facing the unpaid coordinator are burn-out and continuity. Unlike the volunteer's, his commitment is unremitting. He usually operates from home and may get phone calls at any time. Pressure may be put upon him by therapists and he will be tempted to undertake the most difficult and urgent projects himself.

It is usually difficult to find an understudy who will take over when the coordinator resigns. Thus there is the worry of continuity and indeed the

very existence of the group may be threatened if suitable successor cannot be found.

It is a miracle then, that the positions of honorary coordinator are filled.

The Nature of a Project

In general, each problem presents a new challenge to the volunteer. He is required to be an inventor on demand and knows that the product of his labour is needed. What a contrast to the inventor who has a "solution in search of a problem"! However, there is often the uncertainty of success or of client acceptance.

In comparison with an industrial project, development costs must remain minimal and there is usually no possibility of another attempt: the volunteers are expected to be right first time although modifications can and often are made.

Also, time is usually of the essence since client's circumstances can change quickly and his/her motivation to utilize the device can flag.

Working under these constraints is often very exciting to technical volunteers. The keen ones ask for a new project as soon as the last one is completed or work on two or three concurrently.

Scope of Activity

Because volunteers can undertake a great variety of projects in many different situations, it is perhaps easier to define the scope in terms of what should be excluded.

It is the author's opinion that volunteers should not construct exact equivalents of equipment which is available commercially. Admittedly, the cost would usually be much less but the client would have to wait much longer. Also, conflict would arise between the voluntary organisation and suppliers of equipment. TAD has adopted a firm policy against such duplication but this does sometimes result in heartbreaking situations where the client cannot afford the commercial item, no third party funding can be found and volunteers could build an equivalent very cheaply.

Where volunteers work far from a large city, in a locality where commercial products and information thereon are not freely available, there is enormous temptation to produce equivalents and even replicas of commercial items. The temptation arises because of the difficulty and cost of bringing equipment from the city and perhaps having to return it if it does not suit. If chapters or branches are to be effective they must be allowed a fair degree of autonomy and this makes it impossible to enforce policies such as the one under discussion in a rigid way. Consequently, one must expect that occasionally rules will be broken and an equivalent of a commercial item will be produced by the volunteers.

It is seldom appropriate to involve a volunteer in a project which requires him to become an unpaid member of a permanent rehabilitation team. An example of this is the fabrication of seating within a hospital or other

institution. There is a fine dividing line between offering voluntary service to a client through a rehabilitation professional and filling the need for a permanent paid engineer, technician or orthotist. The coordinator has to make these sometimes difficult decisions and protect his volunteers from possible exploitation.

Notwithstanding the above, it is sometimes possible for technical volunteers to make valuable contributions in fields which are thought of as preserves of permanent rehabilitation professionals. A TAD volunteer has developed a hand splint for a person with severe arthritis in which he has used the outside sheath of a bicycle brake cable. This provided the necessary support and gave the client the freedom to rotate the hand which would have been impossible with the conventional splint.

Where a rehabilitation engineering service exists, it is, of course, much better equipped to solve engineering problems connected with orthotics, prosthetics, gait analysis, etc.

Very few volunteers are willing to take on development projects which need many hundreds or perhaps even thousands of hours. Usually such a project will frustrate the client because it will take too long. There are, however, exceptional volunteers who are so skilled and so dedicated that they will successfully complete a major development project in a relatively short time by working on it several days per week. One should be wary of the siutation where an individual client is waiting with baited breath for the outcome of a development project.

The above exclusions still leave a vast arena in which volunteers can work very effectively. They can build simple and, if necessary, complex systems to help a child operate a computer, an old person to get out of bed, a disabled driver to enter an automobile or a high level quadriplegic paint by mouth. The list is truly endless. The most inventive volunteers are more stimulated if the solution seems impossible.

Cooperation With Rehabilitation Engineering Centres

Predictions that voluntary efforts will be made redundant by the establishment of Rehabilitation Engineering Centres (RECs) have proved to be wide of the mark. In most cases, the kind of work done by the two services is quite different.

Where they are not restricted to research and development but are allowed to give client service as well, RECs usually concentrate on such things as specialised seating systems, gait analysis and work associated with prostheses and orthoses. They could, of course, undertake many more types of work if funding were available. There are some areas where overlap with volunteers' work could occur, such as customised seating, standing frames and mobility devices. However, this is not a problem if the two agencies cooperate closely. There are sometimes great advantages to the client from such cooperation. Certain projects demand the rehabilitation engineer's

extensive experience with the human body as well as some of the specialised technical skills and resources of the voluntary organisation.

It is important that flexibility and goodwill between the two groups be actively promoted to enable joint project work, cross-referral and agreement on demarcation.

The potential of volunteers to contribute is sometimes underestimated by paid, qualified rehabilitation engineers, particularly where the latter are not familiar with the nature of voluntary projects and do not realise that the contributions are complementary. A well managed voluntary group with high standards of design and workmanship can and does earn the respect of experienced rehabilitation engineers.

Advantages of the Voluntary Approach

The voluntary rehabilitation engineering organisation has several advantages:

—a volunteer can afford to spend a great deal of time on a specific project, investigating, discussing, designing and constructing.

—a volunteer can become involved in the client's life and practical problems more deeply than an employed rehabilitation engineer (some volunteers have formed friendships with clients).

—a matching process can be used to find the best specialist for the job from amongst a large group of volunteers, eg. a communications engineer, a computer programmer, a skilled woodworker or an instrument maker. No rehabilitation engineering service could afford to employ an equal variety of specialists.

—a good geographical spread of volunteers ensures an efficient, local service. Ideally, the volunteer is the client's neighbour but in practice one must be satisfied with a lesser proximity and, in general, more volunteers will be found in the affluent parts of a city.

—the volunteer usually deals with the client as an equal, not as a rehabilitation professional who tends to be seen by the client as a person in authority. This facilitates good communication.

—the volunteers often willing to provide an ongoing maintenance and modification service to his past clients.

Limitations of Volunteers

TAD experience has shown that it is, in general, unwise to involve a volunteer in a very major project requiring hundreds of hours. Very few volunteers are able to make such a contribution without causing dislocations in their private lives. Also, because the volunteer works part-time on the project, completion can take a long time. There are, of course, always a few extraordinary volunteers who love the work so much that they dedicate enormous amounts of time and energy and who complete very ambitious projects quickly and effectively. Usually, volunteer projects should not exceed say 100 hours.

Very few volunteers are prepared to make batches of aids. This is because batch production requires neither inventiveness nor client contact. Other agencies have to be found for batch production, such as training centres, jails or commercial manufacturers.

Projects requiring certain very specialised facilities are also unsuitable for volunteers. An example is vacuum formed seating and whole body supports which require capital investment, space and expertise which volunteer engineers or technicians cannot be expected to provide.

Rehabilitation professionals are usually unwilling to attend meetings with clients and volunteers outside normal working hours. This excludes volunteers who are fully employed in industry from participating in projects which require input from such professionals.

Certain rehabilitation engineering work involves a regular weekly session, e.g., a seating clinic or a communication clinic. It is not realistic to expect volunteers to commit themselves to such a regular activity. Their private lives must be respected: the right for family activities, travel, etc. Retired people sometimes take extended leave between projects.

Extensions to the Volunteer Corps

It is sometimes possible to involve groups such as trainees, apprentices and prisoners in the batch production of aids. If successful, this approach is of value to both sides: the clients and the workers. Three factors are vital for success:

—a group of workers with adequate workshop skills.

—close liaison by a competent technical person working for the volunteer organisation.

—an interested, motivated supervisor in charge of the trainee or prisoner group.

The liaison and quality control work is time consuming and demands continuity. In general, it requires a staff member, e.g., coordinating engineer.

As a rule, educational institutions are unlikely to be a useful source of help as they have their own agendas and time scales which do not match the needs of individual disabled clients. A typical student project takes anything from six to eleven months to complete and some never get finished. It is unfair to raise a client's expectations and then to make him/her wait for so long.

WHY THE TAD CONCEPT WORKS IN AUSTRALIA

The Australian society is deeply imbued with the volunteer spirit. Voluntary organisations complement the work of government agencies and provide many services in the health and welfare sectors. Australian volunteers contribute millions of hours of work every year.

The community understands that voluntary organisations need financial support and this makes fundraising possible though not necessarily easy.

Companies, clubs and individuals help with donations of funds, goods and services.

There seems to be a strong desire on the part of many citizens to help others, to "give something back" to the community.

TAD appears to offer the only outlet for volunteers who wish to exercise technical skills and creativity. There is, in this country, a pool of technical professionals (often retired) who have sufficient time, equipment and financial resources to do extensive voluntary work. Such a contribution cannot be expected from people who are struggling to make a living or who are fully stretched in their jobs and working under stress.

The TAD Organisation

Technical Aid to the Disabled has a formal company structure, with a Board of Directors, a Chief Executive and a small staff as follows:

Client Service Coordinator—receives and assesses requests for assistance, responds by providing information or referral or by allocating the problem to a technical volunteer; liaises with volunteers, therapists and clients/parents; evaluates completed projects.

The Client Service Coordinator needs a large range of skills including interviewing techniques, some elements of occupational therapy, some knowledge of technology, and very good communication skills.

Coordinating Engineer—provides technical support to Client Service Coordinator and volunteers; assesses hazards; decides whether projects are within the scope of TAD; takes responsibility for safety. This position requires a very versatile engineer, with good mechanical and electronics knowledge and a sensitivity to individual human need.

Librarian—collects and classifies information; ensures retrievability; liaises with other information providers around the world; provides information required by clients and Client Service Coordinator.

Administrative Assistant—provides skilled secretarial and clerical support.

In addition to the above, TAD has an administrative/fundraising section which works intensively to raise some $150,000 p.a. (1987) and takes care of accounts, mailings of the quarterly TAD Journal and all other administrative work.

TAD has no workshop facilities of its own. It is, in fact, a very diffuse organisation—each volunteer works in isolation, in his own home workshop and most do not attend regular meetings. This makes good telephone and written communication essential.

TAD has seven regional branches in the state of New South Wales and one in the Australian Capital Territory. Each branch is governed by a committee composed of local people. Such a committee typically includes two or three of the volunteers, at least one occupational therapist, a businessman and sometimes a medical practitioner. In the day-to-day work, the key person is

the technical coordinator, usually a retired engineer who handles all the requests, allocates projects to volunteers and liaises with health professionals.

Independent TAD organisations also operate in Victoria, Queensland and South Australia. The great distances involved preclude a monolithic organisation and each TAD group has its own board and management, mostly honorary. A loose Federation ensures exchange of information and unified approaches to Federal Government.

At the time of writing, the Federal Government has, for the first time, allocated a grant, amounting to $216,000, to the TAD Federation, to be distributed to member organisations.

Facts and Figures

TAD in Sydney has over 200 technical volunteers who complete about 800 projects for people with disabilities each year.

Referrals can come from any source (relative, therapist, teacher, etc.) and self referral is encouraged.

There is no means test or other restriction on eligibility.

The demand for information has been growing exponentially and the number of people served each year has grown to 5,700.

The organisation employs three full-time and five part-time people and has a budget of $250,000 (1987).

It publishes the quarterly TAD journal whose circulation is 5,000 copies.

The TAD Project

A project is initiated in response to a request for help if:

—no adequate commercial item is available.

—the job is within the scope of TAD volunteers' capabilities.

A volunteer with suitable skills and equipment is selected, if possible in the client's area, and the project is offered to him. He may wish to see the client and learn more details before accepting. On acceptance he discusses the problem with the client, and rehabilitation professionals who may be involved and, in case of a difficult problem, with TAD staff. The client is given a cost estimate for materials and an approximate completion date. Generally, the client covers material and volunteer's mileage costs—all overhead costs are covered by TAD.

Where necessary, the volunteer provides operating and maintenance instructions and shows the client how to operate the equipment.

A trial period ensues, during which the user becomes familiar with the equipment. A month after completion the Client Service Coordinator checks that the client is satisfied and offers further assistance if necessary.

The volunteer is encouraged to document his work and to supply drawings, specifications and photographs to the TAD library.

Whom Does TAD Help?

The service is available to any disabled person, regardless of age, financial status, kind of disability, or its permanence.

The system works best when a volunteer assists a disabled person face to face. There are, however, situations where the request is less direct; an organisation, a hospital or a school may ask for a piece of equipment to be used by more than one person or a batch of identical items may be required. Institutions usually delegate procurement to a purchasing officer who tends to treat the request as a commercial order. Experience has shown that this is likely to create problems, mainly because equipment should be designed in close cooperation with client and therapist. Also, TAD cannot commit itself to short delivery periods when the work is done by a volunteer. Where suitable contractors exist, the institution is referred to them. Where they do not exist, TAD endeavours to help but insists on direct contact with the client or rehabilitation professional.

Batch production is seldom undertaken by volunteers. However, it is sometimes possible to find sources of free skilled labour, e.g. apprentice or other training centres or jails. For the last four years such centres have been supplementing the work of volunteers and have been producing standing frames, posture chairs, corner chairs and simple alarm devices. Time consuming liaison by the coordinating engineer is essential to ensure good quality and adherence to drawings and specifications. Detailed working drawings must be prepared which is not the case when a TAD volunteer does the job.

The Information Service

TAD has links with many rehabilitation agencies in Australia and abroad and continuously exchanges information with technical workers in these agencies. It also actively acquires relevant books, periodicals and articles for its collection which is the best in Australia in its field. It also holds slides, photographs, videos, drawings and a number of prototypes which are used for trials and for exhibitions.

Requests for information come from all parts of Australia and sometimes from overseas as well. They come from people with disabilities, their families, rehabilitation professionals, government agencies, etc.

Where to Get More Information

Write to the Executive Engineer, T.A.D., P. O. Box 108, Ryde, N.S.W., 2112, Australia (phone: 02/808-2022).

Subscription to the quarterly TAD Journal is available. Send $20 in Australian currency to the above address.

A Brief History of TAD

Because of my personal involvement in the organisation I have found it more convenient to write this chapter in the first person.

The TAD concept was born when I started building equipment for disabled people in Sydney in 1970. My first client was Mary Case, a young post-polio quadriplegic, who was taking a Bachelor of Arts degree by correspondence. Her need to alternate periods of study and rest demanded a hi-lo bed which she could not afford. A hospital bed was converted by means of a motor/gear box unit from an old washing machine, at a total cost of $50 and made it possible for her to continue her studies. The change to Mary's life was a great motivation for me to continue this work. The news of this success spread and resulted in further requests for help from disabled people.

After two years it became obvious that the need for simple technology was great and that the efforts of one man would be totally inadequate. The Institution of Engineers Australia Journal published a short letter from me in June 1973 in which I called for help from other like-minded engineers. Twelve responded, of whom eight were in Sydney and four in Melbourne.

The group of eight included mechanical, electrical and civil engineers, some with excellent hands-on skills. One was a lecturer at the New South Wales Institute of Technology and provided a link with this institution which was later to prove very valuable. Being a better organiser than a workshop man I naturally fell into the coordinator role and. while still doing some projects, allocated others to fellow-volunteers.

The potential of our group was soon perceived by several astute executives employed in associations of disabled people. They helped us to establish a committee and frame a constitution, then to apply for a government grant. It is interesting to note that we, the engineers, did not recognise the full potential of the activity, nor were we convinced of the need for a committee, a constitution or government funds!

In 1975 Australia had the first Labour (Socialist) government in 21 years and its policies included support for innovative community activities. It was thus not too difficult to obtain a seeding grant of $13,000 (exactly equal to my salary in industry at that time). The arrival of this grant was rather a jolt to the committee, which would have been short on administrative and organisational expertise, had it not been for our three friends from associations of disabled people. With great excitement and some trepidation, I offered myself for the position of coordinator and was eagerly accepted (after resigning from the position of committee chairman). The salary was only $9000 but job satisfaction was to prove immense.

The important postion of chairman was filled by Jim Dods, a quadriplegic who, until his injury in a traffic accident had been sales manager for the Lincoln Electric Company.

A sheltered workshop provided an office for $5 per week and there I found myself with a desk, a telephone and a filing cabinet. What next?

Three tasks immediately confronted me:

—continue the client service with the help of our volunteers (by then 30 in number)

—publicise the service in rehabilitation circles.
—recruit more technical volunteers.

Within six months it became obvious that the government grant would not be repeated (the Labour government was sacked by the Governor General —that story is now a dramatic part of Australian history) and a new challenge was added: fundraising, which is anathema to most engineers and appeared to me as totally impossible as well as unpalatable.

There was no one to help me at the office—I was totally on my own. Had it not been for a dedicated honorary secretary and an equally devoted treasurer, both of whom often worked till 1 a.m., I am sure we would have failed. It was not easy to be separated from them by a sprawling city of 3 million people. A disabled volunteer 25 miles away provided an alternative telephone number where messages could be left while I was out of the office.

There was absolutely no fundraising expertise in our committee and I soon realised that there were only two choices: learn the fundraising game or give up the whole activity, which was by this time proving to be increasingly useful and valued by disabled people and by therapists.

Not being a natural salesman I looked for a low key, non-confronting approach and found the solution in mail appeals. There were no funds for this purpose but a lecturer friend had access to a Hewlett Packard micro computer coupled to an old fashioned electric typewriter (with hammers!) Even composing the appeal letter was a problem for an engineer used to writing only technical reports. However, a skilled helper was found and my friend and I settled down to letter production every Sunday, in the deserted university laboratory. Using a business directory as a source, we sent 2000 letters to large and medium local corporations. The response was astounding: $15,000 which was sufficient for one year's operation (this was 1976/7). We have never been able to repeat this success rate, nor have I heard of anyone else who has.

In the meantime, the demand for the new volunteer service grew as therapists and groups were informed through talks and articles. My shyness and inadequacy as a public speaker was a great impediment and I had to set about overcoming this obstacle as well. The personal development which the work demanded has been one of the greatest rewards—a wonderful opportunity for growth.

In parallel with the increased demand, I pursued intensive recruitment work to attract more volunteers through technical and in-house periodicals, posters and talks to technical groups.

By 1978, the group had grown to 118 volunteers and the workload was such that a professional client service coordinator became essential. The New South Wales Government responded to TAD's request for funds and an occupational therapist was appointed to a 20 hour per week position. There resulted an almost immediate improvement in standard of service. We were

fortunate to attract a therapist who enjoyed learning about technology from me and from our most talented volunteer engineers.

TAD's first regional branch was established at this time at Bathurst, a town of 20.000 people 130 miles west of Sydney. A small group of volunteers was co-opted by a keen volunteer coordinator and commenced work in close cooperation with the local rehabilitation centre.

An increased level of activity brought with it much clerical and telephone work but the budget of $18,000 did not allow the employment of a clerical assistant. The only possible solution was to recruit suitable administrative volunteers which proved impossible because the office was located in an industrial area. Also, the 9ft by 12ft office was far too small and had no privacy or daylight.

Fortunately, with the help of a sympathetic and influential medical rehabilitation specialist, we were able to secure three nurses' bedrooms in a vacant nurses' home in the Royal Ryde Rehabilitation Hospital. Not only was the additional space a boon but the pleasant residential suburb in which TAD was now located proved to be a constant source of dedicated skilled volunteers who have been, and still are, helping with typing, telephone work, book keeping, library support and other routine tasks. We have created a happy environment in which people enjoy working and interacting with others.

The workload generated by the need for fundraising, administration and publicity left me with an increasingly inadequate amount of time for the essential role of technical support and coordination, without which the service cannot function effectively. An engineer was required to advise on design, watch safety, interview and train new volunteers and solve knotty technical problems on the spot. We were to suffer from the absence of such a specialist until we were able to appoint a part-time coordinating engineer in 1983. The current engineer combines 40 years experience in mechanical, electronic and instrumentation with a strong feeling for people, resulting in another quantum leap in quality and professionalism.

Interestingly, for the last eight years, TAD has not employed an occupational therapist although it seems to be the right profession for the job. Client service coordinators have been drawn from the welfare and nursing professions. The most successful is the current occupant, an ex-nurse with a varied experience in business, marketing and community organisations.

She not only organises projects competently but is also very skilled in documentation, public speaking, mounting displays and organising seminars.

In the first eight years, seven regional branches were established in the state of New South Wales and one in the Australian Capital Territory. They were all set up by local people who saw the need for the TAD service and were excited by the concept. Six branches have survived and two additional ones were formed in the last three years. In 1980, with the number of people

helped reaching the 1500 per year mark, the administrative load demanded the appointment of an administrator (office manager).

It became obvious at that time that information held in the project files is important both to volunteers and to members of the public, be they therapists, disabled people or students. A retired professional librarian was co-opted to organise the information and to acquire relevant material. The library has become an increasingly important resource and has answered 4254 enquiries in 1986/7. It holds not only books and project records but also technical articles, periodicals, slides, photographs and videotapes. TAD has, for the last five years, employed a three day per week scientific librarian who has fallen in love with her job. In a small room she has assembled the best collection in this country of literature on rehabilitation engineering, which is meticulously catalogued and instantly retrievable.

The TAD Board has gained in strength and diversity over the years. It was very valuable to have a severely disabled chairman for four and a half years—he gave us many useful insights and acted as an in-house consultant. The board used to meet in his tiny nursing home bedroom which was always overheated. Having learned of the value of such a person, we sought out other knowledgeable disabled consumers to stand for election to the Board. Engineers are always in the majority but we also have a lawyer, a retired executive, a senior banker and the Dean of an engineering faculty and a retired senior military officer. An important Board member is the director of the Independent Living Centre which is a display and information centre on aids. Four Board members are active technical volunteers and one of these is also honorary journal editor. The last chairman, a prominent academic engineer with a strong interest in rehabilitation engineering, has served TAD for eight years. The search for a new chairman has been one of my most difficult tasks as there are few prominent engineers who wish to be actively involved in a small volunteer body and have sympathy for people with disabilities.

Our current chairman is such a person—an engineer who has retired from the air force with the rank of Vice Marshal. He has a strong sympathy for the cause and is keen to be actively involved. He is likely to provide a new brand of leadership which will open the next chapter in this exciting story.

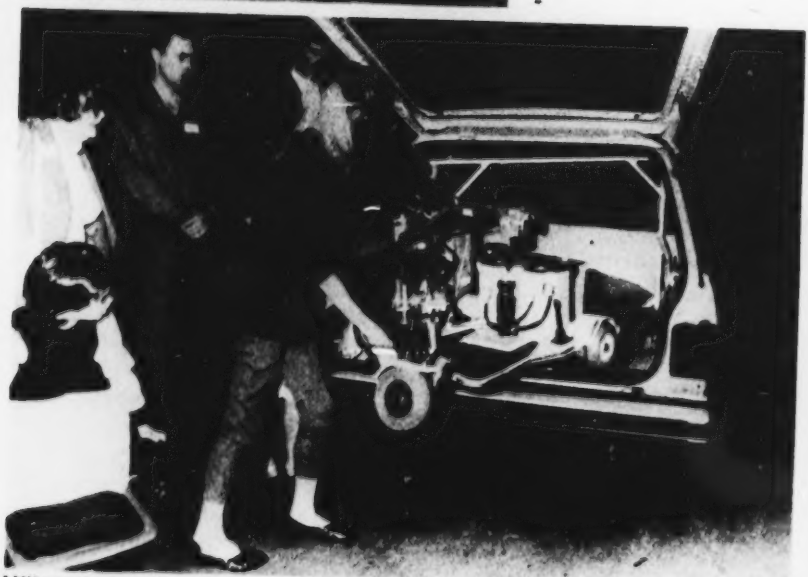
TAD CASE EXAMPLES

CLIENT: Jenny Triganza

Disability Profile: Multiple sclerosis—able to walk short distances with the aid of a walking stick. She is very unsteady on her feet and has suffered severe loss of strength in both arms and legs. She tires easily and often suffers from cramps in her legs. Jenny is 32 years old.

Problem: Jenny uses a BEC three-wheel scooter for mobility around the house and for shopping expeditions with her two young children, Ian and

Seat and steering column have been removed and the scooter body is attached to the jib for lifting. The chain bridle gives a straight lift above the scooter's centre of gravity. Jenny operates switches on the hand-held control box to perform the whole lifting and slewing operation.



Lifting completed, Jenny guides the scooter to its chocks while the mechanism slews its load.

Natalie. The BEC scooter can be disassembled and the parts lifted into the rear of her station wagon for transportation. Jenny, however, is too weak and unsteady to perform this task and consequently is robbed of her independence. Her atttempts to manage outings alone, calling for help from passers-by, leave her exhausted and demoralized.

Solution: Fingertip-controlled electrically operated hoist system to lift and transfer the BEC three-wheel scooter into rear of the Bluebird Station Wagon.

Project Design and Construction: Dennis Brown, Eric Ingman, Alan Every.

Description and Operation: The operating mechanism and support for the hoist are contained and shielded in the rear left corner of the station wagon luggage compartment.

Jenny performs the lifting and transferring functions simply by operating two switches in a small hand-held control box with a flying lead. One swith controls lifting, the other slewing.

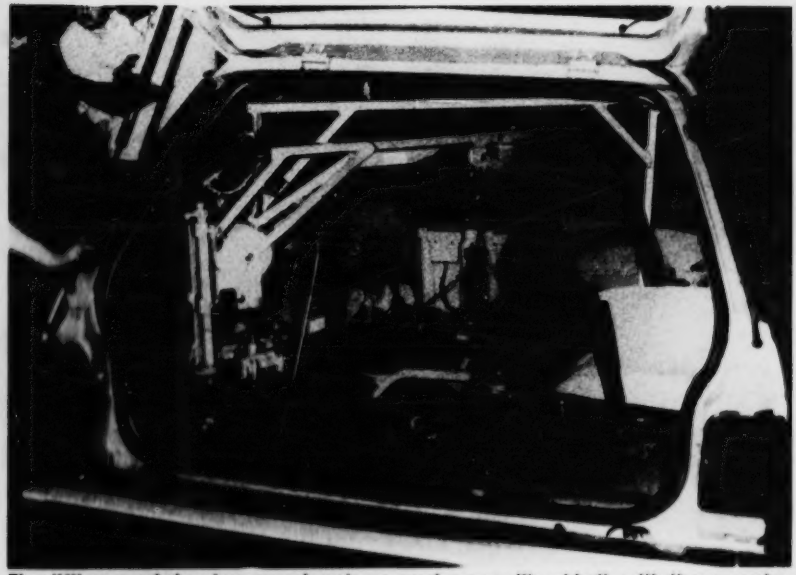
Before the lifting procedure begins, Jenny attaches the hook to a chain lifting bridle which is fixed permanently at two points to the main chassis members. The lift then takes place through the center of gravity of the scooter.

The operation of this miniature slewing crane is quiet and smooth and takes only minutes to complete. No exertion is required of the user to lift and transfer the BEC scooter. Especially when loading the scooter, the operator must guide the load with her hand to be sure that the scooter is placed firmly against the back of the passenger seat. Only in this position will the scooter fit into the loading space. To remove the scooter, the operation is reversed.

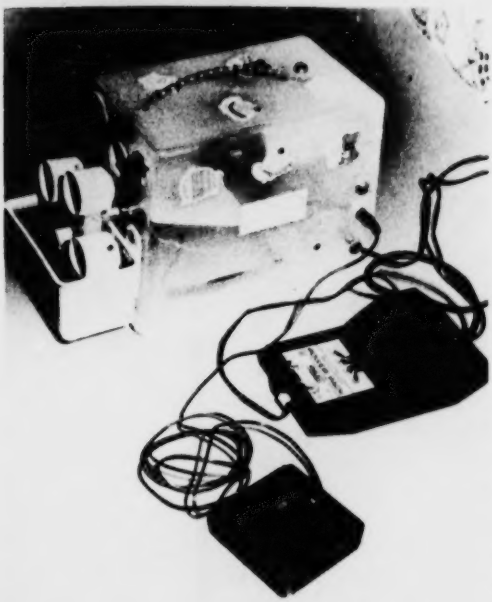
Technical Details: The solution to Jenny's problem involved three factors—her disability, the weight and dimensions of the scooter which gives her mobility and the spatial capacity of her motor vehicle. Accordingly, the project entailed developing a system which would work within the space available to accommodate the lifting-transferring device and the mobility aid. This project was one of the most extensive undertaken by TAD during the year. It involved more than 250 hours of voluntary work and more than $800 in components.

Fitting required making painstakingly accurate hardboard patterns of the station wagon's luggage compartment floor from above and below, measuring the extremely variable vertical space beneath the contoured roof and studying the vehicle's sub-frame in detail to select a spot to mount the hoist which was clear of the petrol tank, spare tire, etc. To provide a secure anchorage for the hoist, steel backing plates above and below the floor are fitted.

Lifting is achieved by a worm drive winch powered by a 12-volt boat anchor winch motor. The worm drive prevents run-back in the event of electrical failure.



The lifting and slewing mechanisms and crane jib at left, with the scooter snugly in its travelling position.



The bubble machine—75 hours down the track. The switch pad (foreground) starts and stops the machine. Power comes from the transformer pack. The translucent freezer box gives a jelly-fish like impression of the works which blow air through the white nozzles as they rotate through the soapy water and up to the vent in the front of the box.

Traversing brings the second motor into operation. A 12-volt window winder motor drive coupled by chain and sprockets to the winch post are used.

Motor capacities were tested exhaustively to determine a maximum operating speed for lifting and swinging the weight of the scooter without overloading the motors. (Since the motors were designed for quite different applications, little or no relevant data was available from suppliers.) The strength of the hoist jib itself was tested, with repeated lifts and transfers of a bag of cement and cement blocks.

The cable was springy, and the turns which remained on the drum when the load was off showed a tendency to loosen into larger coils which tangled when the load was reapplied. A tapered drum was machined so that under load, the cable would wind neatly onto the smaller diameter. To prevent the cable from springing when the load was off, a spring-loaded nylon pad similar to a brake shoe was fitted behind the drum. The pad applies pressure to the exposed surface of the cable on the drum at all times.

Electrical Controls for the two bi-directional motors consist of two switches in a small control box which activate four automotive relays. Limit switches prevent over-run at the furthest extremes of the jib's extension.

Positioning the scooter within the limited storage space is necessarily precise. As further insurance against movement when the station wagon is in motion, there are metal stops over which the scooter's wheels' are settled.

The hand-held control box which governs these functions is no larger, or heavier, than a good-sized paperback novel.

BUBBLE MACHINE

The delight and wonder experienced by a child blowing bubbles is well known.

The process is so simple—use some soap, make a ring with finger and thumb, pick up a film from the bath water, give a puff, and the bubbles are on their way.

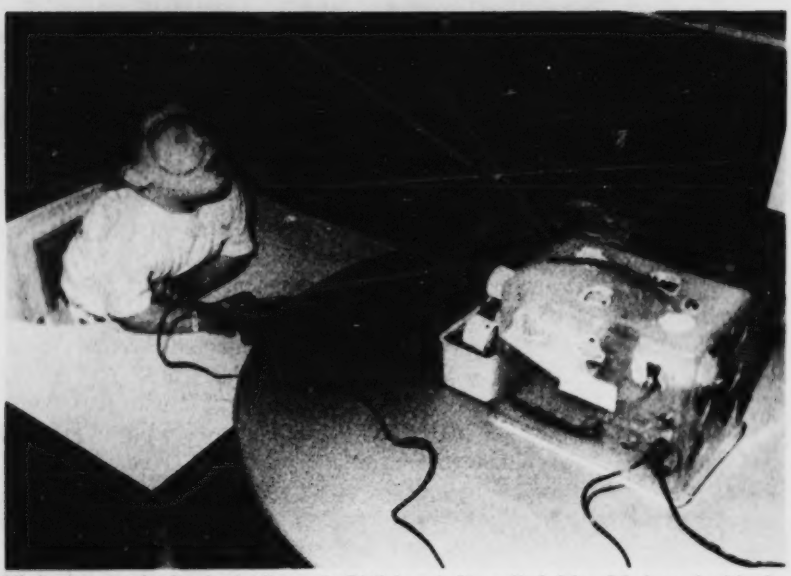
Out of doors, a quick puff on a wire ring dipped in detergent will set the bubbles dancing on the breeze.

But there are many children who are denied this pleasure, because they lack motor control or have other disabling conditions.

It was to help a group of these children that Alan Every took on the job (the fun job, he thought) of making a bubble-blowing machine.

The project originated from a request by Nickie Wiles, a teacher at the Allawah Babies Hospital at Dundas, NSW. Nickie theorized that a bubble machine which could be controlled by a simple switch pad would offer more than the fun of bubbles. Watching the erratic path of a bubble would improve eye tracking. Bubbles hitting and bursting on skin would give unusual stimulation. Switch operating would also have benefits.

About 75 hours of "fun" later, Alan perfected the bubble machine.



Nicholas, a student at Allawah Children's Hospital, tries his hand at bubble blowing—with astonishing results.

Nickie reports that the machine does all that she had expected when writing her brief and also has the unexpected effect of significantly lengthening the concentration span of her students, so well does it hold their attention.

The unexpected side effect in the Every household was that trails of soap and detergent laden water tended to make carpets dirty. Alan will do any further jobs of this type in the bath or out of doors, we are reliably informed.

The bits which went into the final machine include a plastic kitchen container for soapy water; a small freezer box; a 12-volt car ventilation fan; a 6-volt 8 r.p.m. geared motor; a 12-volt 1-amp power pack and a switch pad.

Most of the time spent by Alan was devoted to finding a nozzle configuration which would allow the bubbles to break away without immediately bursting.

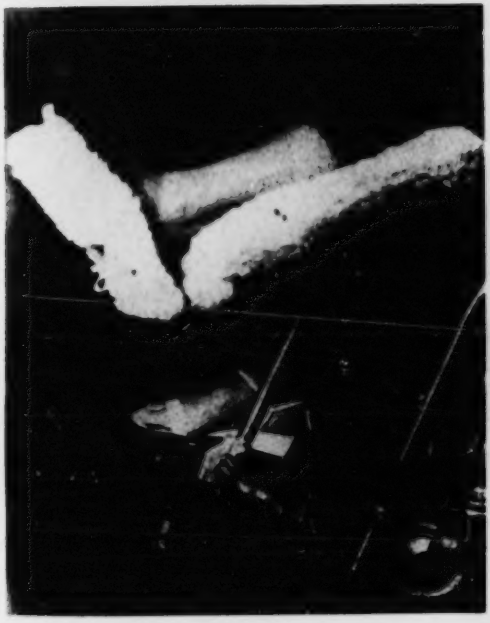
The final solution was to use two concentric, short lengths of PVC pipe which are carried slowly into the container of soapy water and past the vent in the machine case out of which the fan blows a gentle stream of air.

For further information on what did and did not work, contact the TAD office, quoting File 71.38.

TAD has no workshop of its own but each of its 200 plus volunteers has one. TAD volunteer Norman Evans has a large workshop and many skills.

Volunteers with up-to-date knowledge of electronics are scarce. Their contribution is extremely valuable in solving problems in communications and remote control. TAD co-ordinating engineer Alan Every is a volunteer in his spare time.

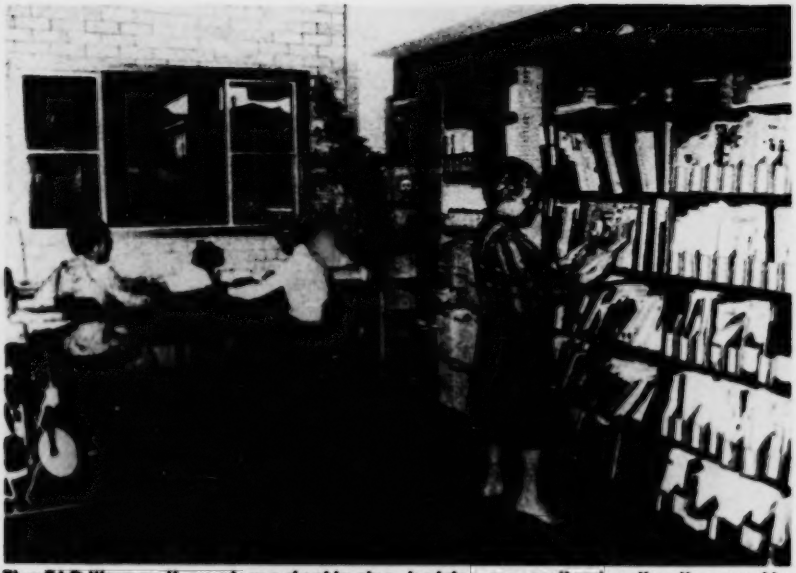
An important rule of the technical co-ordinator is to provide to volunteers information on special materials and techniques. TAD co-ordinating engineer Alan Every is second from the right.



The fully adjustable leg rest was developed by a volunteer for a person who is unable to bend her knee. It is fully adjustable, comfortable and very successful.

Unemployed apprentices who continue their training in a government funded centre provide an ideal extension to the TAD volunteer corps. Standing frames and posture chairs are suitable products.

The TAD project starts with an assessment and problem solving session. Here the client presents her problem to volunteer Stephen Plummer, co-ordinating engineer Alan Every and client service co-ordinator Elizabeth Young.



The TAD library, though modest in size, holds an excellent collection and is constantly consulted by lay and professional people.

ISRAEL

DISABILITY MUST NOT NECESSARILY HANDICAP DAILY LIFE—MILBAT IN ISRAEL

Daniel Barak, Mechanical Engineer, Chief of the Scientific Services Department at The Weizmann Institute of Science.

FOREWORD

When, for whatever reason, a person's ability to use one or more of his limbs or senses diminishes, we define his situation as a disability and the person as a disabled. Today, by using suitable equipment, it is possible to prevent the disability from handicapping the person's daily life.

"Don't try to make life easy for me. It will never be easy, just make it possible." This was said to me by one of my disabled friends while we were discussing the design of a technical aid for him, and it has guided me in my work ever since.

Fifteen years ago I was confronted for the first time with the problems of the disabled when I was requested to solve a problem of an injured and disabled young man who stayed at the hospital and could not summon the nurse and whose mother and girlfriend took turns sitting at his bedside around the clock. He had a spinal cord injury, could barely move his hand and could not contract his fingers to form a fist. Therefore he could not grasp the switch to call the nurse when necessary.

In my department, I am in charge of approximately fifty engineers and technicians. Our job is to assist the scientists in their research by creating for them the equipment they need. In the Scientific Services Dept. there are various workshops, as well as units of instruments design, glass blowing, graphics, instruments maintenance, electronics and welding. Neither I nor anyone of my staff had any previous background in any work related to Rehabilitation or to Rehabilitation-related Medicine, and the research done at The Weizmann Institute, for which we provide our services, is not related to these fields either.

Mr. Barak is also Chairman and co-founder of the non-profit organization MILBAT: The Israel Center for Technical Aids, Building & Transportation for the Disabled.

When the abovementioned problem was presented, I remember the thoughts that went through my mind, as if it were today: 'we could project a weak laser beam at his eyelid which would be covered by a silver shade of cosmetic eye-shadow. The patient would aim the movements of his head so that the laser beam would reflect from the eye-shadow on to a photo cell, which in turn would activate a relay that would summon the nurse.' Today, when I remember these hi-tech ideas, I smile to myself, but then, lacking experience and knowledge, I took for granted that all the simple and obvious solutions had already been tried. Unfortunately, we all know that this is not always the situation

Since that case, and after fifteen years of developing technical aids for the disabled individual, I know that one should never assume that the simple solution has already been tried, or that only an expensive and complicated device, such as a laser or a computer, is the best for solving the problems of daily life of the severely disabled.

INTRODUCTION TO MILBAT

MILBAT is an information center, a place where we have a wide and varied display of aids intended to assist the disabled in their daily lives. The visitor can try out the items on exhibit, get more information about them, and find out which one of them can be of maximal assistance.

The display includes items manufactured locally and abroad, as well as prototypes which may be of interest to manufacturers or to the disabled. We provide information about the equipment and addresses of outlets where it may be purchased. We follow up on the quality of the product and on the maintenance service provided by the manufacturer or agent. The manufacturers and agents, on the other hand, benefit from the exposure their products receive via MILBAT's exhibit. MILBAT reserves the right to determine which items to exhibit and in which way.

The items on display fall into standard functional categories, such as: personal care, work and education, transportation, computers, sitting, motor vehicles, communication, sport & recreation, special equipment for children, special equipment for the aged.

MILBAT does not handle medical equipment such as prostheses. We often joke that we do not need a prescription from a doctor, but rather from a plumber or a technician.

We have put up two signs at the entrance to MILBAT, which are self-explanatory.

1) MILBAT's recommendations are not binding with regard to determining eligibility.
2) The manufacturer/agent is exclusively responsible for the quality and working order of the product.

Since the existence of MILBAT depends on donations, every visitor is kindly requested to make a contribution.

Minimal contribution

Disabled visitors, family members and groups of up to four members	$ 7.00
One-session counselling for rehabilitation personnel and other professionals	$ 7.00
Multi-session counselling	$17.00
Groups of five people and above (per person)	$ 2.00

Counselling and information will be provided regardless of contributions.

Users

MILBAT's services are required by rehabilitation personnel, occupational therapists, physicians, nurses, physiotherapists, architects, engineers, agents, manufacturers, and of course disabled persons and their family members.

MILBAT's services are also sought by various organizations and institutions, such as the ministries of health, defense, labor & welfare and transportation; Israeli health-insurance organizations, assessment and rehabilitation centers, the National Security (equivalent of Social Security), various organizations of disabled persons and schools.

Visiting MILBAT

Visits to MILBAT are preferably by appointment, prearranged over the phone. This enables our personnel to plan their timetable to deveote a sufficient amount of time to each visitor.

So far we have not advertised MILBAT via the media. The information passed by word-of-mouth within the rehabilitation profession creates an overwhelming work load, and we cannot keep up with our daily work, to say nothing of all our plans and goals.

MILBAT passes on information in many different ways, whether on a one-to-one basis, on the phone, in writing, or in day-seminars and workshops.

Meetings and Day Seminars

We initiate, organize and host meetings, day seminars and workshops with test-cases on all of the subjects which are of interest at the center. We use teaching-aids which enable instruction to the individual disabled person.

MILBAT holds international meetings, hosts specialists from abroad, including the coordination of their visits and lecture timetables.

THE HISTORY OF THE FOUNDING OF MILBAT

It took me about two years of creating custom-made aids for daily living to realize the fact that in all of Israel there did not exist an information center for disabled persons, where they can see equipment and try it in order to check its ability to solve their daily problems. This would be a self-evident first step to take before beginning to develop a custom-made device. I was amazed by this fact, which eventually became the turning point in the creation of MILBAT.

Obviously, the need for such a center did not occur to me only, nor was its founding a one-person effort. Through my activity of helping disabled people, I met various rehabilitation professionals. Many of them naturally realized the need for an information center, each of them seeing it through the viewpoint of his own field, visualizing what such a center should be like and how it should operate.

Various government ministries established committees which dealt with the subject such as the ministries of Health, Labor & Welfare but I found out about this only much later.

Finally, MILBAT was founded as a result of a series of meetings between the late Professor Raphael Rozin and myself. Prof. Rozin was head of the Rehabilitation Department in a central hospital in Israel; chief physician in the Department of Spine-Injury Rehabilitation; and also head of the Israel Rehabilitation Society.

On the ground floor of the same hospital, an area of approximately 1500 square feet was made available to us. This area was originally intended for the hospital's air-conditioning system and other machines. Finally, only an air-compressor and the main electrical switchboard were left there, and we received the remaining area for MILBAT. This was not the ideal solution, but as we say in Hebrew—When receiving a horse as a gift, one does not examine its teeth.

Two interior designers who had attended a lecture of mine rose to the challenge and designed, free of charge, the complete interior of the Center. The result was attractive, unpretentious and practical. A building contractor and several other people joined the team of volunteers applying the recommendations of the interior designers. They built partitions and doors, painted, installed air-conditioners, etc. The size of the area at our disposal made imperative its maximal use. The library, for example, also functions as a partition wall.

At that time, too, I was constantly going in and out of fabric and carpeting shops trying a piece of velcro on hundreds of different fabric and carpeting samples. Finally I found a relatively inexpensive wall-to-wall carpet to which one-half of the velcro adhered well. We covered most of the walls and

partitions with it, and a considerable part of the exhibit is attached to the wall by this method, enabling us to remove various items, use and return them, and also to easily change the exhibit when necessary.

Location

The classical dilemma regarding such a center—should it be within the area of a hospital or not—was solved for us by the very fact that this is what we were given, but the dilemma exists to this day. The advantages of the proximity of the hospital is of course the daily give-and-take between MILBAT and the hospital: we are on the spot to help and we also benefit from the professional consulting given by the hospital's various departments. The advantages of being in town and not near a hospital would be that The Center would be more easily accessible to the public, and that when you came to receive information you would not have the feeling of "going to the hospital."

Financing

I assume that every organization like ours has financial problems, not only initially to get it off the ground, but also later keeping up with the constant operating costs.

We collected $90,000 in the beginning, of which $60,000 was donated by a philantropic fund of the Israel Discount Bank, as their donation for 1981 which was the International Year of the Disabled. An additional $20,000 was given by Israel Joint, another philantropic fund, and $10,000 was donated by a family from New Jersey.

MILBAT TODAY AND IN THE FUTURE

Today we employ one occupational therapist full time, two others half time and one speech therapist half time. The rest of our activity is covered by volunteers.

Unitl recently, all of MILBAT's services were given free of charge. However, due to our difficult financial situation, we began requesting a modest contribution from the visitors (around $7.00 per visit).

When evaluating the balance of expenses versus incoming funds, it is evident that if we do not manage to obtain additional funding it is not at all clear how we can avoid closing it down in another year or two. However, it is evident that we won't close MILBAT down, as its activity is far too important.

Part of the items on our exhibit were loaned to us free of charge by agents who are interested in displaying and demonstrating their products. Unfortunately, these agents are not powerful enough economically to become the sole source of our income, and therefore we must keep seeking private as well as government funding.

Library

The library in MILBAT contains information about the equipment, including catalogs and manufacturers' information leaflets, as well as

research papers and varied professional literature. We are planning to establish and operate a computerized information service which will be connected with similar databases and libraries throughout the world.

But this is our dream for the future. Meanwhile, we are still unsure as to the classification system we would like to use. This reflects the worldwide situation, with various systems being used in different countries, one of which we will eventually adopt.

Meanwhile, the library is operated using the "boxes" system, in which material on each topic is put in a separate box. The classification is mixed: according to disability (blindness, deafness, learning disabilities, etc.), according to activity (kitchen, hygiene, environmental control, etc.) and sometimes according to the manufacturer/supplier.

Additional Needs in the Future

While operating MILBAT, the need for the following has become evident:

a) A mobile exhibit and source of information which is able to travel to distant locations.
b) A mobile technical workshop capable of providing technical assistance, as well as performing adaptations at the disabled person's home.
c) A lab for motor-vehicle adaptations, as well as driving instruction.
d) A lab for the adaptation of wheelchairs.
e) A seating clinic.
f) More space; more employees.

Volunteers

The volunteers at MILBAT give their support to the smooth operating of the center in different areas such as by adapting equipment for a specific problem. Some of our volunteers are highly qualified specialists in different field such as computers and motor vehicles, as well as architects, engineers. In the north of Israel we have a group of almost thirty technicians and engineers as the largest branch of MILBAT volunteers.

Although historically MILBAT's activity stemmed from the activity at the Weizmann Institute, today the course of information and assistance is reversed. The disabled person seeking help is first directed to MILBAT and only later, if he requires an adaptation to an existing device or an individual solution, is he directed to our volunteers' activity.

The Individual Approach

As we have already mentioned, it is possible to overcome most of the handicaps due to disability. Using existing equipment or that which will be developed in the future, disabled people can lead active and interesting lives. Awareness of the developments around him and a strong desire to help himself can enable even the severely disabled individual to live independently, work at his profession and support himself.

During the years of my work with the disabled persons, I have come to the conclusion that the individual approach should be emphasized as far as possible. This we do in MILBAT where we demonstrate standard equipment in general, and even more so when the disabled person requires the help of a volunteer to solve his problem. Therefore every effort should be made to stress the individuality of the solution, as each problem is unique and no person has ever lost his individual personality when becoming disabled.

A Paradox

The tendency to develop and create special equipment for the disabled person gathered momentum. However, I think that the developing of technical equipment for the entire population will eventually lessen the need to develop equipment especially designed for people with disabilities. A solution for the disabled person will be available eventually using standard existing equipment.

Here are some examples:

It is a well-known fact that the computer was not originally developed or created for the disabled. However, there is no doubt that its contribution to the disabled is far greater than to the nondisabled. The nondisabled person can use the computer as a word processor (among other things), whereas the severely disabled person who cannot write or speak can sometimes use the computer for typing to substitute writing or speech, which otherwise would have been impossible.

An electrical toothbrush, an elevator and a car with an automatic gear are further examples of equipment not initially intended for the disabled, but which assists the disabled more than the rest of the population in the impact it has on their lives.

Mistaken Attitudes

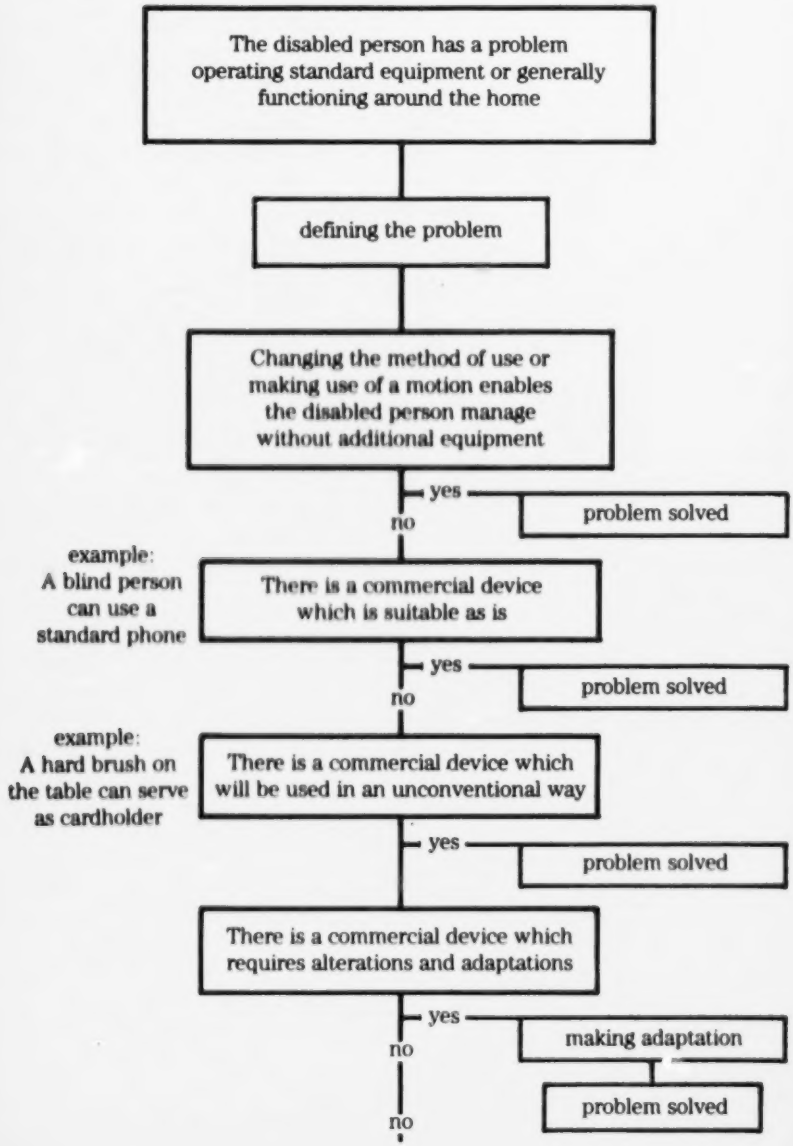
A person who, for the first time, meets a severely disabled person may react with the following thoughts: "Who am I to be able to help?" or: "If it is at all possible to help under such circumstances, certainly only highly qualified people can do it." or: "Highly advanced technologies such as computers, lasers or robots are required here." Such attitudes can also be found among those who are in a position to help or who are looking for assistance. In many cases, it is possible to minimize the handicap by using various technical aids, some of which are surprisingly simple.

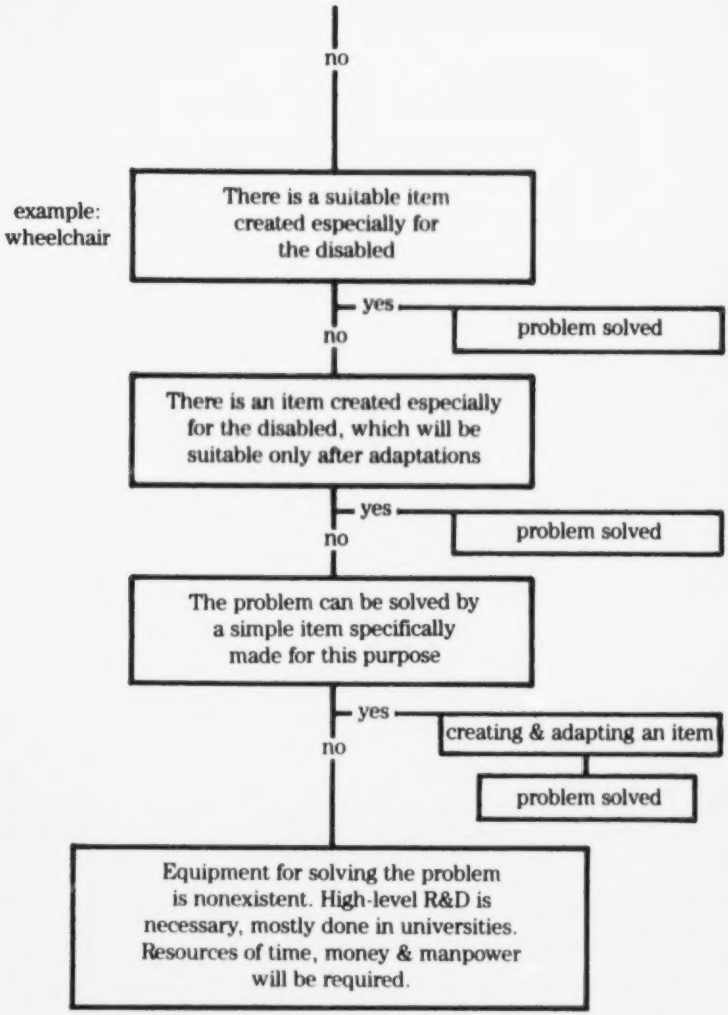
The Involvement of the Disabled Person

The most important factor is the wish of the disabled person himself to become rehabilitated. It is obvious that the best and most suitable piece of equipment will not work if the disabled person rejects it. Therefore, it is of major importance to include the disabled person in all the stages of the search for a solution and to listen to his opinion.

Stages of the Search for the Right Solution

Recommended steps to be taken for finding and adapting of the appropriate item.:


The disabled person has a problem operating standard equipment or generally functioning around the home
defining the problem
Changing the method of use or making use of a motion enables the disabled person manage without additional equipment
yes
problem solved
no
example: A blind person can use a standard phone
There is a commercial device which is suitable as is
yes
problem solved
no
example: A hard brush on the table can serve as cardholder
There is a commercial device which will be used in an unconventional way
yes
problem solved
There is a commercial device which requires alterations and adaptations
yes
making adaptation
problem solved
no
no


no
example:
wheelchair
There is a suitable item created especially for the disabled
yes
problem solved
no
There is an item created especially for the disabled, which will be suitable only after adaptations
yes
problem solved
no
The problem can be solved by a simple item specifically made for this purpose
yes
creating & adapting an item
problem solved
no
Equipment for solving the problem is nonexistent. High-level R&D is necessary, mostly done in universities. Resources of time, money & manpower will be required.

The Volunteer's Ten Commandments

The following Ten Commandments were written with a smile and were intended for the volunteers in MILBAT, but I am sure that anyone who does volunteer work will agree that they apply not only in Israel.

1. Before you start solving a problem—study it.
2. Break down each problem into sub-problems.

3. Use, as far as possible, the handicapped person's ability to function and avoid unnecessary devices.
4. Whenever possible, use existing devices—don't "re-invent the wheel."
5. Be extreme in the simplicity of the solution.
6. Aspire to simplicity, but don't forget aesthetics.
7. Remeber that the handicapped person's opinion (and not yours) is the one that matters—he (not you) will have to live with the solution.
8. Don't be hurt if your suggestion is not accepted.
9. The desire to help is not an alternative to medical knowledge. Be careful not to cause damage.
10. Recruit new volunteers.

GREAT BRITAIN

REMAP OF GREAT BRITAIN
A VOLUNTARY TECHNICAL AIDS SERVICE

P.H. Hammond, East Regional Organizer

INTRODUCTION

In January 1987 Jim Tobias visited the UK, as a Fellow supported by the World Rehabilitation Fund Inc., to study the REMAP organisation.

The Tobias report presents an excellent account of REMAP, outlining the history of the organization, the environment of health care and rehabilitation in the UK within which REMAP operates and the organisation and activities of the voluntary panels comprising REMAP.

The present paper aims to supplement the Tobias report, primarily in terms of some finer detail of REMAP panel activity and of some aspects of panel structure and distribution.

The Need for REMAP

REMAP operates in the context of conflicting trends in the development of technical aids for the disabled in the UK. Thus, on the one hand, the increasing availability of mass produced aids means that more of the commonly encountered problems of disability are alleviated by commercial products, albeit those which can command a mass market. On the other hand, UK government fiscal policy acts to discourage the provision of state funded facilities for the design and manufacture of technical aids for individual disabled people, whilst encouraging market driven manufacture and charitable activity.

As disability is, almost by definition, idiosynchratic, and the UK market, except for a range of basic equipment, is relatively small, it follows that the need for one-off technical aids will not diminish with time. Furthermore, it seem inevitable that state funded designers and constructors of one-off technical aids, a unique UK example of which is the Technical Aids Service in a hospital medical physics department at Newcastle-upon-Tyne, and which is described in the Tobias article, will not be a normal feature of the UK scene for the foreseeable future.

It may be instructive to examine typical panel activity as reflected by the actual referrals to a sample of REMAP panels during 1987. The sample contains 17 panels representing about 16% of the total but not necessarily representative in any statistical sense. The total number of referrals in the year (385) were distributed as shown in *Fig. 1*.

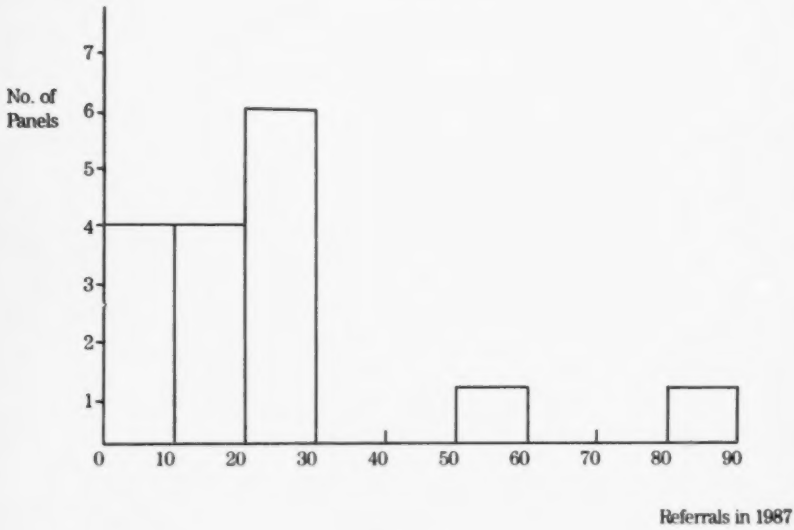


FIGURE 1.
Referrals to 16 panels in Eastern Region, REMAP
Total Referrals 385 Mean Rate 24

There is no evident reason to believe that the high referral rate in one area and a correspondingly low rate in another reflect different absolute needs for technical aids in any straightforward sense. The difference must lie largely in the operational aspects of panels and of the interaction of the various parameters discussed below.

Panel Operation

A voluntary panel is a complex human organism and many interacting parameters influence its "productivity." Some of these are:

a) The degree of leadership and commitment exhibited by the panel chairman.

b) Number of enthusiastic medical and para-medical members bringing referrals.

c) Number of engineering members having ability to carry out construction in metal or wood.

d) Quality of workshop facilities available to panel members.

e) Existence of a team spirit between panel members, especially between disciplines.

f) Willingness of the engineering members to take on project work rather than just to talk about it.

g) Degree of awareness among the medics and para-medics of techniques available to the engineers.

h) Degree of informal contact and interaction between the engineers and para-medics outside of the formal meetings of the panel.

Some of these items are fairly self-evident requirements of a productive panel. Other items will bear further examination.

Cooperation Between Medical People and Engineers

Though the point is difficult to prove, I believe that many problems of disabled people never surface at panel meetings because the medical side does not recognise that a technical solution, within the competence of the panel, can be achieved. In terms of a conventional manufacturing company the medical side is the "marketing force" of the panel and, unless the therapists have a good working knowledge of the capabilities of their engineering colleagues they may miss leads. Also, the panel whose technical members lack knowledge of relevant engineering techniques may miss out on solutions when presented with problems. Less seriously, the technical bias of a panel will influence their problem solving. Typically one panel may incline to electrical or electronic solutions and another to mechanical, both producing equally valid technical aids.

Another factor often overlooked is that successful solutions are most likely to evolve when the problem is studied at first hand. Some panels spend too much time on round table discussions of possible solutions to complex problems posed by para-medics before at least one of their members has seen the client, ideally in the company of the para-medic, to assess what the problem really is about or, better still, inviting the client to a panel meeting to demonstrate the problem.

Workshop Facilities & Meetings

The question of workshop facilities is vital. Some panels have members with their own comprehensive facilities and this is an ideal situation. Other have to rely on a sympathetic attitude by company or college workshop managers to achieve their objectives. Inadequate workshop facilities clearly reduce completion rates and thus tend to inhibit referrals. In this connection, the best situation is undoubtedly when panel members have personal access to well equipped workshops. Relying on company or college workshops can lead to delays when the REMAP job has to take a low priority place in a job list or where its completion is tied to a students project work.

This latter point leads naturally to the question of interaction outside the

formal panel meetings. Some panels take this to extremes and reduce the number of formal meetings to two or three per year. Referrals may then be handled centrally by the panel secretary and referred directly to an appropriate member. Though panels can operate in this way their referral rate is usually much lower than those which meet regularly. At least one panel, serving a UK county, holds meetings at one of four sites in the country in turn and has members and resources in the region around each site as well as a centrally based secretary and chairman.

The question of panel finances was not included in the list of factors above. This factor seems to be virtually unrelated to the productivityof a panel. As the Tobias report points out, panels normally have very modest bank accounts and are more often embarrassed by an excess of funds rather than the reverse. Panels differ in their financial arrangements. Most take the view that materials should not be paid for by clients. These costs are often paid by the organisation for which the referee works, whether Social Services Department or hospital, or by a relevant charity. Clients sometimes make donations to the work of panels, as do Local Authorities, Lions and Rotary clubs and other fund raising bodies. Most panels pay the necessary travel costs of their members on request.

Insurance

Insurance is also not on the above list and is virtually taken for granted by most panels. In fact it is a central service, handled by RADAR. The operation of REMAP would not be possible without insurance coverage indemnifying any panel member against injury to clients resulting from his or her design and constructional activities. The history of litigation under this insurance cover in the UK is very briefly stated. In the 24 years of the existence of REMAP, covering the activities of around 2000 panel members, there have been NO claims against any member for injury to a client from a technical aid. Of course, there could be a claim tomorrow—that is the nature of the risk. But the record to date must surely be significant. In my experience, a rather higher risk may be the possibility of a claim for compensation by a commerical manufacturer against a panel which accidentally undercuts his business or denigrates his products. such an eventuality is not covered by the REMAP insurance. Also not covered is the chance of damage to clients equipment whilst in the care of a panel member. Many panels take out their own cover, for a modest sum, against such risks.

Panel Distribution and Life Cycle

Distribution roughly reflects population density. Thus there are few panels in the low population density regions of Scotland, Wales and Northern England. Elsewhere panels usually centre on medium sized towns or conurbations. Panels tend to have an intensely local flavour, serving their well defined community rather than feeling themselves to be part of a national

organisation. Each panel serves a population of at least 100,000 people. There are 94 panels in all.

No doubt there are as many and varied parameters determining panel creation as determine operation. An attempt to list these must be incomplete but they include:

—Number of domiciliary occupational therapists serving an area.

—Existence of engineering companies, higher education establishments, military bases and other sources of technical support and expertise.

—Intensity of the effort which a regional organiser gives to the job of initiating a panel.

—Degree of commitment shown by senior medical staff, whether themselves panel members or not.

—Existence of special schools or units serving disabled people.

—Being in an area of high unemployment, surprisingly, does not seem to help. The vast majority of panel members are either employed or retired.

Though many factors, of which the above are examples, influence the origin of a panel, the key one is to identify and encourage the relatively small number of people with relevant skills and commitment within the target community. In practice this means that out of say 100,000 people, one is looking for 30 who will become panel members of long standing. Finding this one in 3,000 can be rather like looking for needles in a haystack!

Currently, an experiment is being carried out within a comparatively small area of the West Country, where a full time development officer of RADAR has the task of setting up and supporting panels serving much smaller populations than the current national pattern. Some of these panels are based on small self-contained towns like Chippenham (pop. 20,000) and Marlborough (pop. 6,000). So far the prognosis for these new panels looks good. If they become established then some of the current thinking about panel density and national referral rates may have to be modified sharply upwards!

Panel Lifespan

The oldest REMAP panel, in Cleveland, has flourished for 24 years and, in general, panels have long lives.

The healthy panel is in an equilibrium state in which the commitment and contribution of the medical and engineering members is well balanced. This balance may become disturbed, typically for one of two reasons. If the medical and para-medical side do not produce a flow of referrals, the engineers fall away due to lack of interesting work. Conversely, if the engineers respond too slowly in designing and constructing requested aids the medical and para-medical members become disillusioned and lose interest.

Most panels seem to oscillate gently betweeen these two states but have sufficient cohesion to survive and flourish. Occasionally, instability sets in and a panel dies away, usually with a whimper rather than a bang! When a

panel has disbanded, for whatever reason, only time and changing personalities or needs in the area will allow a new panel to be successfully reformed. The cycle of instability which sometimes leads to the dissolution of a panel is illustrated in *fig. 2*

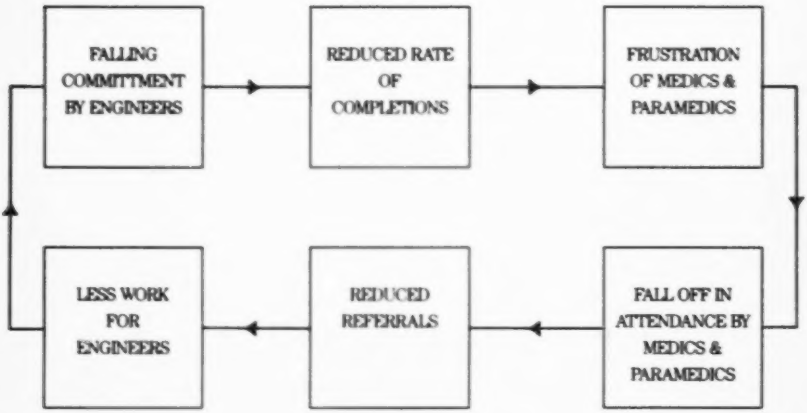

FALLING COMMITTMENT BY ENGINEERS
REDUCED RATE OF COMPLETIONS
FRUSTRATION OF MEDICS & PARAMEDICS
FALL OFF IN ATTENDANCE BY MEDICS & PARAMEDICS
REDUCED REFERRALS
LESS WORK FOR ENGINEERS

FIGURE 2
A cycle of instability

The REMAP Award

The range of work done by REMAP panels is very wide. It is therefore somewhat unfair to select illustrative examples at random. However, in 1987 a REMAP national award was founded in conjunction with the NAIDEX exhibition organisation. A brief description of the award winners entries may therefore provide a representative glimpse of the work of the organisation. Even so, it should be pointed out that notice to panels re the 1987 award was short and the selection was made out of only 28 projects submitted.

The short list of 12 projects from which the winners were selected indicates the wide diversity of the projects tackled by panels. The Lothians panel in Scotland submitted a range of ingenious adaptations to garden tools for a client with cerebral palsy affecting his hands. Bath put forward a feeding aid for a person with violent hand tremor; from Surrey came an electrically powered leg-raiser to assist a client to get into bed. East Sussex offered a dressing aid for a man who could not lift his arms; Hertfordshire North an adaptation to a commercial bath hoist to enable bath hoist to enable the user to operate it despite his inability to use the original equipment. From Lincolnshire came an extensive adaptation to a commercial stacking truck with which a paraplegic man could decorate his home from floor to ceiling. A "reward" game dispensing candies, for use in a special school, came from Humberside and from Huntingdon, a jug kettle tipper.

The four Award winners are also drawn from widely differing areas of need.

BERKSHIRE PANEL Tilting Commode/Easy Chair

The tilting commode is, in fact, for a lady in her late 80's who has very limited bending ability in her knees and trunk. When her thighs are horizontal her back can only reach a semi-reclining position and her legs cannot be brought to the vertical. Her requirement was for a commode chair onto which she could place herself in a standing position and which would tilt her. The solution was to provide a commode pan fixed in space surmounted by a tilting seat with a backrest and footrest coupled to it by a system of pivots and levers so that the movement between the components match the client's hip and thigh movements.

In use the lady mounts a footplate from a walking frame, grasps the arms on each side and leans backwards onto the then vertical backrest which moves backwards with her. At the same time the footrest comes upwards and forwards until the seat is horizontal and her legs and back have reached their maximum allowable bending positions. The commode is then ready for use. Leaning forwards and slightly pulling on the arms causes the reverse movement and placing the user in a vertical position again. The arrangement takes the "down" out of sitting down and the "up" out of standing up. So comfortable was the commode that the lady insisted on it being equipped with an optional conventional seat and uses it as an easy chair!

CENTRAL NORFOLK PANEL Swallowing Reminder.

The swallowing reminder was in the form of a brooch, worn by the client, which contained an adjustable timer which sounded a quiet buzzer to remind her to swallow, at appropriate intervals. This client dribbled constantly unless reminded to swallow since her swallow reflex had been suppressed by her condition. The specification set by the panel was a device which would produce an audible tone burst at intervals adjustable from 30 to 60 seconds at a just audible level and be light and small enough to be worn like a brooch.

The electronic circuit developed by the panel used conventional cheap components on which various clever miniaturising tricks had been played, was packed into a case 60mm by 10mm thick and is capable of even greater miniaturisation. An example of the ingenuity displayed was the reduction in size of a conventional piezo crystal sounder by sawing it down to dimensions of 2mm by 4mm using a diamond coated dental saw!

YORK PANEL Portable Foot Stop

The York portable foot stop is a delightfully simple device for a lady with M.S. who retains some mobility, e.g., is able to transfer herself from bed to wheelchair, but is liable to fall and cannot then get up unless she can brace her feet against a wall or other, immovable object. Since a fall could take place anywhere in the house a portable "immovable object" was a possible solu-

tion. To meet the need the panel devised a "chock" for her foot with squares of "file card" secured to the base. File card, used by fitters for cleaning files, behaves rather like a metallic Velcro but with much increased gripping power. This grips the carpet effectively enough to take a horizontal load matching the full thrust of a leg, without in any way damaging the carpet.

The "chock" is a carefully designed structure, using lightweight materials for easy portability, with a concave foot rest to ensure that sideways sliding of the foot was prevented. The area of file card found adequate to take the load without slippage was about eight inches square.

WEST DORSET PANEL Femur Stem Remover

The West Dorset panel is based on the Winfrith Atomic Energy Establishment in Dorset. It therefore has access to very high grade workshop facilities without which the panel's entry would not have been possible.

Stainless steel joint replacement prostheses sometimes break in service. The surgeon then has to extract the broken end of the pin from the femur. At the break the pin has a cross section of typically 13mm by 19mm.

Normal surgical practice has been to cut a window in the side of the femur at the tip of the broken pin and then to knock the broken piece out from the tip end. This procedure clearly weakens the bone and extends the operation time. The panel have designed and made a device which grips the broken end of the pin, using what is effectively a small vice the jaws of which are tightened by a collet. An impulse hammer runs down the cylindrical extension of the vice jaws and applies shocks to the end of the pin, thereby releasing it, whereupon it can be withdrawn. The panel have been made up two sets of pin removers (with a range of sizes for different pin types), one based in Dorset and the other in the Midlands. These are dispatched by post to any surgeon requiring them. Apparently, due to the relatively low incidence of pin breaks, reduced still further by the development of improved pin materials, this satisfies the current UK need.

This latter project illustrates a minority branch of REMAP work. At least two panels have orthopaedic surgeons amongst their members and take on some projects originating in surgical requirements for which no satisfactory commercial instrument or appliance exists.

CONCLUSIONS

REMAP, though now in it's 25th year of existence, still fills a major need in the provision of individually targetted technical aids for the disabled. Despite the much increased availability of commercial aids since the inception of REMAP, the need for the voluntary design and construction service remains as strong as ever. Voluntary panels, as they operate in the climate of British society today, form an effective system for delivering technical aids. The indications are that the 90 panels currently operating could be significantly increased in number without reaching the point where demand is completely satisfied.

REMAP DEVICES FOR PEOPLE WITH DISABILITIES
Jim Tobias, Rehabilitation Engineering Consultant (U.S.).

For more than twenty years, something unusual has been happening in Great Britain. Teams of technical whizzes have met up with therapists and social workers and the results have been...the creation of hundreds of useful, inexpensive, custom-designed devices for disabled people. The organization is called REMAP, for Rehabilitation Engineering Movement Advisory Panels, and its effectiveness has been noticed around the world. Many visitors have come to take a look at how it works and its products, and as a recent visitor from the United States, I intend to make this report both a description of REMAP in its context and, perhaps, a guide useful to those of us who would like to build a similar organization on this side of the water.

This study was undertaken during December 1986 to January 1987. I visited several REMAP panels, interviewed several members and officers, and met with a few clients. In addition, I interviewed many people outside REMAP in order to understand how it is seen by other rehabilitation agencies and professionals, as well as to get a picture of how rehabilitation technology operates in Great Britain. I also reviewed some literature, both about REMAP and rehabilitation in Great Britain in general.

A BRIEF HISTORY

REMAP was born in 1964, the offspring of several projects and ideas circulating around Imperial Chemical Industries, Ltd., the British chemical giant. Geoffrey Gilbertson (now Sir Geoffrey) was an ICI Personnel Manager. He needed a device to get around the Billingham plant and asked some engineers to see what they could come up with. Their project was a success; they decided to continue on as an ad hoc group to help ICI employees and pensioners. The organization existed in an amorphous form for a while under several leaders, always expanding. At one point it was decided to "go national". The British Council for the Rehabilitation of the Disabled was approached, and it took the young group under its wing. Norman Brearley, also of ICI, set up several more panels and began expanding in the north as part of his stewardship. At about this time principles of organization were formed and central issues such as insurance were tackled.

In the ensuing years, REMAP set up regions to keep track of the growing number of panels, and took on a National Organizer. Importantly, REMAP cast its lot in with the rehabilitation community as a whole, rather than remain linked only with its technological origins.

The host agency for REMAP is now RADAR, the Royal Association for Disability and Rehabilitation. This is an umbrella agency, containing almost all of the organizations within Britain that are concerned with disability, more than 400. RADAR's primary role is in legislative lobbying and general advocacy for disabled people and the agencies serving them. It has more than

fifty employees and a budget in excess of 750,000 pounds. It is perhaps closest to the National Rehabilitation Association of the United States in its purpose, but has a greater range of activities and public visibility. It provides both a home and a budget for REMAP.

The Executive Committee of REMAP consists of RADAR administrators, REMAP Regional Organizers, and the Yearbook Editor. This committee coordinates national policy and responds to national issues, but uses a very light touch in its implementation. Regions and panels are considered to be autonomous, so interference is kept to a minimum.

There are five REMAP regions, splitting up the country along rough geographic boundaries. The Regional Organizers have about twenty panels under them, and so must travel widely and often. They are the true executives of REMAP, having the widest view of the day-to-day operations. In fact, most of them are or were senior engineering managers and are now retired. Some have fine engineering reputations and a host of contacts within industry and academia. They use these contacts in countless ways, from recruiting new volunteers to locating or "liberating" materials and components for panel projects. Their travel and other expenses are paid, and they receive in addition a few thousand pounds per year salary.

But the local panels are the heart and soul of the organization. It is at this level that all the action occurs: case referral, design, consultation, fabrication, installation, etc. Indeed, many REMAP members are blissfully unconcerned with the doings in the upper levels. They spend their time in direct contact with only their clients and the other members. A later section will describe their functions in more detail.

Rehabilitation Technology in Great Britain: A Brief Description

It would be impossible to understand REMAP's role without knowing something about how other players in the field operate. Britain has quite a number of agencies and facilities that perform rehabilitation technology services, and they interact in a number of interesting ways. I visited only a few of them, but tried to get as broad a picture as possible. The organizations I missed and the ones I saw were not selected scientifically, but were the ones available during my trip. So the outlines below might be characterized as "exhausting but not exhaustive." The descriptions will also include how these organizations work with REMAP, if they do.

Disabled Living Foundation

Disabled Living Foundation is an information service about equipment for disabled people. Operating since the late 1960's, it carries information on more than 20,000 devices and programs. Its Aids Centers are staffed by experienced OT's who can give advice as well as raw information. Since all the equipment is on site, visitors can try out various pieces before making a decision. Information is also available over the phone (22,000 calls last year) and through a series of 22 booklets, listing commercial devices broken down

by category as well as descriptive information. These, subscribed to by local authorities as well as others, are updated every year.

There are 18 Aids Centres, of which 14 are full-size. Their work is coordinated through the Joint Aids Centres Council, which also helps with money, through government grants and private donations.

About half the visitors to the Centre in London are clients themselves, with or without their therapists. The other half are therapists or students who come to learn about the devices on display.

DLF has an active role with manufacturers, giving them design advice and informal evaluation information. Manufacturers will often place new products in the Centres in order to find out the therapists' opinions.

DLF staff will often refer clients to REMAP if they are not aware of a commercial aid meeting the client's need. For its part, REMAP panels, through their OT members, rely on DLF bulletins in their search for commercial devices before they assign a case to a technical member.

Manpower Services Commission

The Manpower Services Commission is a part of the national Department of Employment. Services to disabled persons are provided by Disabled Advisory Service (DAS) teams, which are organized on a regional basis and have members from different disciplines. Often included on these teams are Technical Officers. These people have both a technical and a rehabilitation background, and are responsible for any plans involving technical accomodations. Most of them now have had some computer training as well, so they are competent to deal with changes in work equipment.

There are two programs for technical support. Special Aids to Employment involves the long-term loan of equipment, and accounted for 2740 cases in 1985-1986, averaging 399 pounds. Adaptation to Premises and Equipment involves capital grants to employers for modifying their worksites, and accounted for 165 cases in the same year, averaging 1788 pounds. MSC's policy is said to be very liberal, with easy approval for most cases, if a long waiting period.

MSC has tended to rely on its own Technical Officers, so its links to REMAP are vague, especially because its funding policy lets it purchase devices from the commercial market.

Department of Health and Social Security

DHSS is a government department responsible for some of the equipment for disabled people; principally, wheelchairs, artificial limbs, and environmental controls. Its branch, the Artificial Limb and Appliance Centres (ALAC), handles the actual purchasing of devices, as well as several other functions. Purchasing ofdevices is done centrally, giving DHSS a great amount of leverage with manufacturers. It uses this to enforce design criteria and set performance standards, as well as save money. DHSS does evaluation of equipment prior to its approval, including technical and field trials of all

new aids under its charter. It also looks at a few standard consumer items, like irons, to determine any features which work especially well or poorly for disabled users.

DHSS is now under review, especially the part covering rehabilitation technology. Many alternatives have been put forward to improve its work, often focussing on its financial practices and possibly including a voucher system for the purchase of wheelchairs. Under this a client could theoretically accept one of DHSS's chairs or use the equivalent amount towards a chair of his or her choice. Presently, clients must select their chairs from the DHSS stock of just a few models, or purchase their choice entirely on their own.

Since DHSS operates on a mass scale, its connections with REMAP occur more at a local level, through each ALAC, rather than nationally. Several staff members have been REMAP panel members, and functioned as case referral sources. Here too, though, I heard that the growth in the commercial market means a decline in the need for REMAP's volunteer efforts.

Local Authorities: Health and Social Services

Local authorities are responsible for the actual delivery of health care and related services. As Britain does not have states or provinces, it should be remembered that there are therefore only two real levels of government: national and local. (The National Health Service is, however, divided into regions, then local districts.) Local authorities are responsible, then, for the actual delivery of health care related services. These include probably the most important element regarding adaptive equipment: the domiciliary Occupational Therapists. These OT's are employess of the local authority. In a week of home visits, one of these OT's may see dozens of situations in which an adaptive device would be useful. If something commercial exists, it is generally ordered directly through the local authority. If not, the OT may contact a REMAP panel. Indeed, many panels count one or more domiciliary OT's as members, as they are such excellent sources of projects. They often take a leading role in the life of the panel; several chair them.

Local Authorities: Education

Local educational authorities are responsible for providing special educational programs and materials, and as local authorities differ widely across the geographic and political spectrum, so do the services available. The most enlightened localities offer full computer-based learning, for disabled and non-disabled children. This can mean many adaptive input and output peripherals.

Local authorities have a wide range of national resources, and some are lucky enough to have local or regional centers for training and evaluation. These centers are staffed by experienced special educators, therapists, and technologists, who can suggest the most appropriate aids. An example is CENMACH, the Centre for Motor and Associated Communication Handicaps.

CENMACH is an agency of the Inner London Educational Authority, located at Charlton Park School. It offers advisory services and evaluation of students as well as a full teacher training course in the use of computers and communication aids for the purpose of writing. CENMACH staff travel around to schools and teachers come to CENMACH to get the latest information on devices and software, as well as how to incorporate this information into their classroom programs.

Many REMAP projects are done for schools, from mobility aids to communication devices to toys. Some of these referrals come through school administrations, but most are directly routed to REMAP from teachers and school therapists.

Independent Living Movement

Although a fixture on the scene in the United States for more than fifteen years, the Independent Living Movement is really just beginning in Britain. There are about half a dozen independent living groups, only a few of which have operating offices. The prime focus in Britain, as in the U.S., is attitudinal change on the part of rehabilitation professionals and the public at large. As a prime representative of the "rehabilitation establishment", RADAR comes under some criticism from this quarter, and REMAP is seen as a part of RADAR. The few independent living activists I spoke with who had had contact with REMAP, however, were pleased with its services.

The movement itself has little involvement with technology, but a bi-weekly television show, "LINK", is interested. This show, produced and staffed by several activists and others, is broadcast throughout the nation. Almost every half-hour episode has a segment on technology, whether it is a description of a new device on the market, a conversation with an aid developer, or a discussion of funding procedures. Indeed, a review of segments of twenty or so past shows would be an excellent introduction to rehabilitation technology in Britain.

Hospitals

Several hospitals have departments of rehabilitation engineering. These aim mostly at meeting the needs of inpatients or newly-released patients, but most also offer services to the community at large. For instance, the Technical Aids Service of Newcastle General Hospital provides services to the entire North Region of the National Health Service. This unit was once the Newcastle panel of REMAP; its history is discussed elsewhere in this report.

The Royal Hospital and Home for Incurables is similar, and also has designed items and made them on a small scale for the national market. The head of Rehabilitation Engineering of this hospital is also the chair of the local REMAP panel, as well as a private licensing contractor! He and the other staff members work on their own designs and have low-volume fabrication facilities.

There is also the Research and Development Group at Warley Hospital.

This group both solicits designs from the public and develops its own, in conjunction with St. Batholomew's Hospital. It often hands off successful designs to private industry for manufacture and marketing. They work closely with REMAP and have had several designs from that source, including an ingenious push-along trolley. The Warley group has also made referrals to REMAP when ideas come in that seem too low-volume for their own work.

Disability-Specific Organizations

As in the United States, there are many agencies in Britain that are built around services to people with one specific disability. And many of them have their own initiatives in rehabilitation technology. An example is the Spastics Society, akin to United Cerebral Palsy in the US. The Spastics Society operates some schools and institutions as well as provides services to people with cerebral palsy living in the mainstream. Their technical services are quite broad and include software cataloguing and development and very complete adaptive device evaluations and recommendations. These evaluations run through two days and look at all life functions, often resulting in specific device recommendations. One of the therapists at the Spastics Society said that they generally have at least one device per client which is not commercially available, and this is referred to the appropriate REMAP panel. Their relations with REMAP arre strong, with several staff members sitting on panels.

For people with sensory impairments, there are the Royal National Institute for the Deaf (RNID) and the Royal National Institute for the Blind (RNIB). RNID does a lot of research in telecommunications for people with hearing impairments, and operates a deaf relay network over the telephone in conjunction with British Telecom.

RNIB handles a wide range of technical projects. From employment and training programs to talking computers, from elementary educational aids to geriatric conveniences, RNIB engineers keep up with latest technology and apply it well. They work closely with the Manpower Services Commission to serve visually impaired job seekers. They publish six volumes each year on aids and research, which are distributed worldwide. One of their most dramatic efforts is as device distributor: they handle some 500 aids, selling them at a two-thirds subsidy. This cost them 1.7 million pounds in '85-'86.

They are beginning a volunteer technical program of their own, and have been discussing with REMAP how it might tie in with REMAP's organization.

British Telecom

British Telecom (BT) is the still-integrated, recently privatised national telephone company. It has an Action for Disabled Customers group in its London headquarters. This group consists of half a dozen staff who provide information and technical support for disabled telephone customers. In addition, each district office has an officer assigned to this work. Technical support includes: adapted telephones, inductive couplers for people with

hearing impairments, modifications to pay phones, home alarm systems connected to the phone network, telephone-based speech output communication aids, and support for general and specific research. One research project BT helps fund is to examine low bit rate transmission of sign language.

The services focus on commercial equipment, but special assemblies are occassionally needed. These must be certified as compatible with the telephone system and are registered through the central office, although most often designed and built locally. Commercial equipment is sold or rented through BT sales offices, just as for non-disabled customers. Several sources of help exist for costs, including both private charities and local authorities. In 1983, more than 100,000 people got help with their phone bills from local authorities. If the phone is work-related, the Manpower Services Commission will pick up the cost of any special equipment.

Information services are an important part of BT's effort. They publish a guide to equipment and services each year that describes what is available. They also publish an excellent quarterly called "Dovetail" that includes new information and human interest stories of BT's work in this area.

Their contact with REMAP is slight, but REMAP volunteers are helping them with a project on easy insertion and removal of modular phone plugs.

Communication Aids Centers

There are six formal Communication Aid Centers in Britain, established by DHSS and RADAR in locations that had already been working in this field. The Centers perform client evaluations and recommend devices, help with the training, and act as resource centers for people interested in non-vocal communication. Since they keep a current stock of many devices, and some duplicates, they are an excellent try-out location and may also loan out devices for short term trial.

Some have their own volunteer programs, where people learn about how an aid is used and then tutor the clients, offering a convenient interlocutor as well as taking some of the load off the overworked Center staff.

Residential Centers

The Cheshire Homes are the preeminent residential centers in Britain. There are more than fifty of these spread all around the country. They offer not only a place to live, but recreation and work experience. A few years ago several Cheshire Home staff people began a computer project, seeking to increase the ability of their residents to use computers effectively. Now called COMPAID, it is a separate non-profit organization that has published a book about computers and disability and conducts evaluations and recommendations for clients, both inside and outside the Cheshire Homes.

Academic Developers

Many researchers in academia have taken on rehabilitation technology projects. I managed to visit with a few of them.

At Cambridge, William Harwin in the Engineering Department is working on robotics for disabled children, using the latest technology to create a system whereby disabled kids could sort and build, using small blocks and parts. He also works on robotic feeding aids and workstations and is a member of the Cambridge panel.

Oxford is the home of ACE, Aids to Communication in Education. It is a national center for development of computer software and input devices for disabled school children. Many local educational authorities look to it for advice and visit it often.

Private Developers/Manufacturers

The private market is alive and well in British rehabilitation technology. I visited with Toby Churchill, a speech-impaired engineer in Cambridge who manufactures and markets his own line of communication aids. (These are sold in the States through Zygo.)

David Ridley of Ridley Electronics designs, manufacturs, and markets a line of remote environmental control and alarm devices. Since these use infrared telemetry, there are no wires strung around the user's home, and it is easy to reinstall or relocate the aid.

Voice Control in Cambridge offers a line of very effective voice-recognition environmental controls. These can function across a room and are capable of operating 12 appliances.

POSSUM, the granddaddy of British rehabilitation technology firms, still has its line of environmental controls, communication aids, and typewriters. POSSUM is now developing some computer-based designs.

Before I return to describing REMAP, I would like to recommend that a full study of rehabilitation technology in Britain should be undertaken. This brief glimpse should not be taken for an exhaustive survey. And the unique British system, with its salient contrasts with the United States, deserves to be the subject of a much more conscientious investigation.

Back to REMAP: How Panels Operate

Panels, the local arms of REMAP, are autonomous beings, but they share certain characteristics. Each has a Chairman, a Secretary, and a Treasurer. Some panels have other officers, for example, Publicity Director. Panels meet every month or six weeks to discuss cases in hand and new referrals. These meetings are quite lively, with a thorough and friendly discussion of proposed designs and actual fabrications. Although usually one engineer takes on a project, during this interchange the project is "fair game" and all members present feel free to comment upon its progress. The amount of defensiveness and competitiveness appears very low, and a premium is put on cooperation and helpful suggestions. Members go out of their way to help each other out, especially if a project has gotten behind or is in a difficult stage. The overall impression is one of friendliness and mutual consideration, of sociability as well as concentration on the clients and projects.

A word on structure. When first looking at this study visit, I prepared a list of formal functions, such as case management, design review, etc., and was well on the way to creating an interview form for all my REMAP "informants" , wherein they would describe in minute detail exactly how responsibilities were distributed. Luckily, I never finished these questionaires. I think that if I had sprung them on my "informants", I would have been given some fishy looks. REMAP is extremely informal in structure. All panel members are expected to take a hand in the work, but rarely are separate functions embodied in offices or even made distinct in planning. Rather than spell out responsibilities, panels encourage participation, with their chairs shepherding members only when things fall behind.

The descriptions below, therefore, are extracted from panel meetings and interviews. Indeed, REMAP members might be surprised to recognize that what they do could be defined and pigeon-holed in the way that I have done.

Recruitment

Most recruitment is done through panels. Most often new members will be introduced by one of the present panel members. Some members have had personal experience of disability, and this is their route. Some panels have advertised for members in local newspapers, as well as encouraged the papers to print articles about the panel in the hope that new members will be found (or new clients referred).

Both Regional Organizers and panel Chairs spoke about a key element in keeping panels strong: the balance between technical members and OT's. If there are too few engineers, projects take too long to get done. This causes a drop in new referrals. If there are too few OT's, there are too few referrals to begin with. In either event, engineers start to drift away, and before much time has passed, the panel is very small and inactive.

In order to prevent this, panels take care to cultivate OT's and other therapists as members. They are seen as a precious resource, since they are not only the source of new cases, but they have the valuable clinical information and awareness of commercial devices that the engineers lack. A few panels counted themselves lucky to have, in addition to a few therapists, representatives of the social services office of the local authority. These people were also excellent case sources as well as useful connections to local government.

Finances

Panels all have bank accounts, generally of just a few hundred pounds. They receive donations from clients, individuals, and organizations. Several have been successful in securing grants from their local authorities, since REMAP's work is often highly visible at the local level and it supplements quite well services offered by local government. This was a topic of discussion at four of the five panel meetings I attended. Clients occasionally pay for

materials and parts for their own projects, although this is not expected. One panel adds a 5 pound "fee" to its materials charge for the purpose of sustaining itself. On some occasions sponsoring organizations will donate money for a particular project, covering all or part of the expenses. An example is the donation of 300 pounds by the Musicians' Benevolent Fund to the Croydon panel for the construction of a piano pedal control device for a paraplegic pianist.

At the national level, RADAR appropriates about 50000 pounds for REMAP. This goes to pay the Regional Organizers' salaries and travel expenses, the REMAP Secretary, and related costs. The Yearbook, the only truly national project, does slightly better than break even due to the sale of sponsoring advertisements.

Insurance

The issue of liability insurance has been recognized as crucial to the development and expansion of rehabilitation technology, especially when it is done by volunteers. The spectre of a massive lawsuit based on an injury to an already-disabled client has been freezing initiative in this field for years. How does REMAP deal with this?

Since REMAP began under the wing of huge Imperial Chemical Industries, it was natural to include its coverage within the corporate policy. The underwriter could hardly have objected to this inclusion, given the size of the parent policy. And now REMAP has inherited that policy, a very broad one. It includes blanket coverage for all REMAP members working on approved projects, up to 250,000 pounds. All that is necessary for a project to be covered is that it be registered with the panel and some description of the work be forwarded to national headquarters. (This policy also serves to help collect case and project information.) The premium is about 500 pounds per year. Since this national policy covers only design and fabrication, some panels have separate policies to cover theft, damage, etc., if a device is taken into a panel member's home shop.

Case Management

Panel meetings are built around case reports. Each active case is discussed, with the assigned member presenting new information. Group discussion often clarifies or suggests new approaches as well as confirming the work as it is being done. Cases which have been "hanging around" too long without any progress get special attention from the Chair, but since REMAP is a voluntary organization it is not possible to apply much time pressure to the members. Some clients referred to this as the weakest part of REMAP, and some therapist members had problems with it as well. Especially when the project is for a growing child or deteriorating client, time is of the essence. From my observations, this was taken into account quite well.

There is no formal follow-up. Clients who are not satisfied with a device are expected to, and in fact often do, contact the panel with their complaints.

Most of the follow-up calls are for simple maintenance, also at the client's request.

Competition with Commercial Devices

REMAP has a formal policy of not building aids that are available from the commercial market. It is assumed that one of the main functions of therapists on panels is to discourage re-invention, and in fact, this seems to be the case. REMAP sees its speciality in creating unique, one-of-a-kind devices, suitable for a given individual and a given function.

However, in practice there is not a fussy attitude toward this issue. Volunteers, once alerted to the existence of a commercial aid, are not restrained from creating one remarkably similar in some cases. These cases reflect several instances. If the cost of the commercial aid is seen as prohibitive, members fell that they can build one of their own, and do so for reasons of thrift and to prove a point. The technical challenge inherent in the project can also excite members past the threshold of seeking a commercial device. After all, they are engineers looking for challenges. But overall, only a few real breaches of this policy were reported to me, although the subject came up in most of the panel meetings I attended.

Technology Transfer to Commercial Companies

There is no formal route for technology transfer to companies in the business of rehabilitation aids. However, many members could recall designs with obvious commercial potential being turned over to manufacturers, and two such instances were confirmed by manufacturers themselves. Since by its very nature REMAP shies away from volume production of any size and seeks to concentrate on intriguing, one-of-a-kind projects, there is a natural opportunity for such "handing off". Many individuals within REMAP have other roles that encourage a flexible hybrid approach to these situations. For instance, the head of a small device manufacturing firm was once the Chair of a REMAP panel. The present Chair of a panel is also the head of the Rehabilitation Engineering department at a hospital. The hospital and his private practice build and distribute several models of electric wheelchairs and controllers. And one panel, Newcastle, essentially dissolved itself into the Technical Aids Service, a professional operation producing one-of-a-kind and small volume devices, based in the Medical Physics Department of Newcastle General Hospital. (A note to readers unaccustomed to such unclear lines of authority and accountability: this flexible approach did not bother the REMAP members, manufacturers, researchers, or anyone else I spoke to, who were eloquent in defending its naturalness and effectiveness in delivering usable devices to clients. The system seems to rely on good faith and judgment, rather than strict delineation of responsibilities.)

Starting New Panels

Starting new panels is the responsibility of the Regional Organizer. It

often involves a year's worth of legwork: finding a therapist or two, a home base for meetings, and, most demanding, a cadre of available and well-disposed technologists. Regional organizers report that they have had several false starts in this, most often due to poor timing of recruitment and case referrals, leaving too many engineers with nothing to do or too many clients waiting too long. New panels receive the princely sum of ten pounds to cover their early expenses.

Maintaining Panels

Regional Organizers report that panels have lives of their own. Although some panel members have been with REMAP for a long time, over the course of several years there will be changes in membership. Additionally, there arx always changes in types of cases referred, panel leadership, and external factors such as new commercial devices, services provided by local authorities, and national policies. Any of these changes can have an impact, but it is membership that has the most often reported effect. Losing a key member, especially an OT or panel Chair, can have a disastrous effect on a panel. More cases were reported of panels faltering by loss of a source of case referral than by loss of technical expertise; engineers seem easier to recruit and keep than therapists or social workers. Another balance that was mentioned was that between working and retired people. Both have their strengths; most panels include more retired engineers than practicing ones, although this depends a lot on the location of the panel near industry or academia. Retired therapists were rare as panel members.

National Functions

There has been no National Organizer for about two years. In the absence of this person, few functions are retained at the national level. They are performed by the Secretary, the Yearbook Editor (himself a former National Organizer), or by the REMAP Executive Committee under RADAR.

1. Correspondence. Mail or phone calls most often request a way to get in touch with a local panel; this is forwarded.

2. Budget. RADAR's budget allocation for REMAP is apportioned to Regional Organizers for salary and expenses, the part-time RADAR secretary assigned to REMAP, accounting, and overhead.

3. Yearbook. This highly readable and interesting publication is edited nationally, including as many projects and panels as possible. As advertising space is sold in it, it typically earns money (4000 pounds in 1986).

4. Liaison. The Executive Committee keeps in touch with other national organizations concerned with disability, most of which are already connected with RADAR. This liaison might have to do with specvific requests for help, information sharing, or general advice.

5. Case Lists. Now being updated, these are to include a description of all projects completed by all panels. The purpose is to avoid duplication of effort

and to bring the panels closer. The Case Lists are prepared from panel minutes, although there has been discussion of a universal case form to be used especially for reporting projects.

6. Design Issues. Occasionally, a design issue will arise everywhere at once, or be recognized as of general interest. Two examples: a recent law mandated the use of seat belts in cars. Since many disabled people have difficulty with the belt buckles, there was a possibility of hundreds of cases arising at once. The problem was discussed at the national level, Regional Organizers took it to several (but a limited number of) panels, who are working on designs. The end result, I was told, will most likely be a set of suggestions that manufacturers might include in their mass-market designs. A case common to several panels was the need for a gas heater valve adjustment mechanism for people with difficulty stooping. (Many British heating stoves have their valves at floor level.) Several good solutions arose over the years, and British Gas was approached nationally about this in order to make the adaptations available to the widest possible audience.

There are plans to alter this present structure. RADAR has a field staff, its Development Officers, who travel around their regions. The plan is to combine the roles of Development Officer and REMAP Regional Organizer. This would bring REMAP closer into RADAR, but is seen by some panel members as giving up autonomy and technical expertise in the leadership.

IMPLICATIONS FOR THE UNITED STATES

Is There a Need?

Three differences between Britain and the US stand out in examining whether we need a REMAP over here. First, we are a somewhat richer country. This has begun to mean that we are willing to spend more for each rehabilitation client. This may yet translate to sufficient money for rehabilitation technology to support a full, for-profit sector of rehabilitation technologists and firms offering a wide range of devices. At present, we see only glimmers of this willingness. But it certainly could expand, reducing the need for the charitable channel.

Second, we are a more business-oriented country. We have a strong predisposition to use private enterprise whenever possible, even if it is not the most efficient way. This pre-disposition would hamper development of a volunteer organization if it were seen as competing with a private, for-profit sector.

Third, we are a larger country. Time after time it was impressed upon me how the relative small size of Britain aids in the continuity of REMAP: distances are less, contacts with industry are easier to maintain, and there are fewer levels of government. Coordinating regions of a volunteer organization would prove much more difficult here than it does there.

There are other issues as well. When British engineers retire, they tend to stay where they were living, rather than move to a sunny retirement

community (a sunny anything being rare in Britain). This means that that person's contacts are still alive, both with the community and with the technical field. Also, the degree of cooperation in general seemed higher than in the States, to this amateur social analyst. Here, when someone starts a successful operation, the first thing that happens is that competitors spring up. There, colleagues spring up, people interested in helping to spread the idea around. This may be idealization, but I believe there is hard evidence about it; in fact, the British themselves castigate their lack of the entrepreneurial spirit, of hustle. It may be the two sides of the same coin. At any rate, the history of volunteer rehabilitation engineering in the United States shows some indication of competitiveness rather than substantial cooperation.

But the argument that I think finesses all the claims that the United States does not need or cannot support volunteer rehabilitation engineers is this: that people keep spontaneously volunteering no matter what. When someone with technical expertise meets a disabled person with a technical need, a natural partnership begins. Neither may consult with anyone else, and no real research may be done, but after a while, a device will be designed and built. It may be a reinvention of the wheel, it may have been designed using its designer's favorite technology, or it may be ugly as sin. But it works and is probably safe. There is probably nothing anyone could do about these spontaneous volunteers: the field is too obviously interesting and important, and strikes too deeply a technologist's need to transform the world in beneficial ways.

The question is really: how can rehabilitation professionals have the largest and best impact on this otherwise diffuse volunteer effort? And I think the answer is: by sponsoring it, penetrating it, strengthening its affiliation with rehabilitation, and providing positive guidance. If the complaint is that these volunteers are uninformed about rehabilitation devices, we should educate them. If they are slow to deliver, we should help with case management. If they condescend to their clients, their consciousness should be raised. And this is all possible: rehabilitation professionals may reject the use of volunteers, but I doubt that volunteers would ever reject well- intentioned rehabilitation professionals with useful information. REMAP panels certainly understand their central role.

For the moment, let us assume a moderate growth in the private, for-profit, professional rehabilitation technology system. There are more firms in the field, more clinicians, and better funding, driving the whole mechanism. Under those conditions, would there still be a role for volunteers? I believe so. Some functions, such as recreation and "quality of life" will always have trouble being funded. Some needs are so specific to an individual as to be unmanufacturable, requiring continuing on-site redesign and maintenance. Some geographical areas will be poor in professional rehabilitation services. Some devices are presently sold by aids companies as a public services, since they are low profit items; manufacturers might be happy to hand them off to a

volunteer organization. An example of this might be battery interrupters or some switches. In these few categories, several thousand cases per year could easily fit.

Add to this the fact that industry will undoubtedly play a larger role in any US setup than it does in Britain. Large corporations will need services of this type themselves (remember REMAP's origin). Why not through their own staff, acting as volunteers? And industries could take on general projects stemming from their own technologies: the telephone companies work on phone access, automobile companies on van and auto modifications. This would put the most powerful resources available to work on significant projects, and ones not taken on by the smaller specialty aid companies. And industry may help in another way. Having access to exotic or high-tech design and fabrication tools, large companies could do low-volume assemblies or components and hand them off to the small aid companies that could not afford that investment in tooling. This kind of hybrid approach should not frighten us! Let's recapture some of the "can do" attitude we seem to have lost in our battle for professional specialization and market-share insurance.

Why Not Just Import the Model?

If we are going ahead with a plan to establish a volunteer organization in the States, can it be a REMAP clone?

Significant cultural differences between Great Britain and the United States (after all, the common language is just a deception) would make it unlikely that a rigid importation scheme would work.

Above all, the professional rehabilitation technology environments are quite different. The United States is a larger market with more sources of funding (although not necessarily much more per capita available for these devices). This means that there are more companies trying to establish themselves in the field and more full-time rehabilitation professionals interested in technology (especially more rehabilitation engineers).

Purchase of commercial devices is done through private businesses here, the medical supply houses, rather than being purchased centrally and distributed through local authorities. This means that our "prescribing authorities" are relatively distant from the technical process, never having their hands on equipment at all, but relying on marketers and other interested parties for information. The role of the local authorities is very strong in Britain and is a large part of what makes REMAP able to work so well. The US rehabilitation system is based more on the state, an unwieldy jurisdiction too large for comfortable coordination and too small for market leverage.

And it must be remembered that sizeable volunteer efforts already exist in the United States. How can these coalesce into a national organization? Can they be prised away from their origins and linked up with each other and the world of rehabilitation? Consider only the Telephone Pioneers, the service group of several hundred thousand retired telephone company

employees. They are based on local chapters, not really available through a central office, and only marginally aware of the rehabilitation community. Yet they have been providing technical services for dozens of years. They do far more than rehabilitation technology; they are a general charity. Can they be encouraged to have rehabilitation technology committees that relate strongly to other volunteer groups and to clinical people?

The factors referred to above would call for an adjustment in plans in trying to organize a similar group in the US. The resources available are staggering in their depth and wealth. (In fact, it may be that the wealth of resources is one of the most difficult problems to address: the embarassment of riches!) But how can we avoid the many pitfalls?

Below is a list of do's and don'ts from my perspective, given the advice I received in Britain and what I saw there:

DON'T declare an organization from above, either from government or within industry.

DO support all local initiatives.

DON'T do a feasibility study. We know this stuff can be done.

DO work with all present volunteer groups, such as the Telephone Pioneers and Volunteers for Medical Engineering.

DON'T expect these groups to give up their autonomy. Offer them central services if possible. How about a one-of-a-kind design data bank to prevent wasted duplication of effort? How about liability insurance?

DON'T expect rehabilitation professionals to volunteer their help. Who wants to have a hobby that's just like their work?

DO encourage agencies and facilities to offer compensatory time if therapists, etc. want to help out with this group. Departments of Vocational Rehabilitation should understand that volunteers will make their task easier; they deserve this support.

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UNITED STATES

VOLUNTEERS FOR MEDICAL ENGINEERING (VME)
By Carole Wayne Forsythe, Executive Director

Mission

The VME mission is similar to that of volunteer engineering organizations in other countries i.e. to provide technical solutions to problems faced by persons with disabilities. Sometimes the problem can be one of affordability; sometimes the problem arises because a solution does not yet exist. VME will tackle both problems. VME also seeks to mobilize the industrial resources of the U.S. corporate economy.

The Service Context

VME volunteers engage in a variety of activities, including:

- design and fabrication, or modification, of assistive devices, both simple and complex
- assist medical professionals and their clients in the use of adaptive equipment
- assist service provider institutions in evaluating, installing, debugging computer technology
- training in computer skills, and job coaching
- design and installation of workplace modifications
- research and development

VME services are used by rehabilitation and medical personnel, by state and local officials, by schools and vocational rehabilitation agencies, by advocacy and consumer organizations, and directly by persons with disabilities.

Rarely is anyone turned away who asks for help. If VME has the skills and resources to ensure success, the project gets attention. However, the focus is on unsolved problems affecting a small group of people, services or devices which do not already exist or cost too much. It is our policy to work closely with clients and clinicians, avoiding competition with other agencies or established business.

Service Process

As described above, requests for help may come from many different sources. A request becomes a VME chapter project when it is approved by the

chapter's Project Review and Approval Committee (PRAC). The PRAC must include a medical/rehabilitation professional and a licensed professional engineer. The committee studies the problem statement, preliminary solution, state of the art, timing, resources needed, potential risks and "property" problems if any. We attempt to avoid making something which is readily available from another source—but if we err in our judgement or knowledge of what is available, it would be in favor of doing something which meets the immediate individual need.

Once a project is approved, the project leader must adhere to certain documentation guidelines, depending on the complexity of the project. For example, a simple project may require a two sentence statement of problem and proposed solution to get approval and funding, and a one sentence project report when done. A complex, highly risky project may require national office approval and certification of the drawings by a licensed professional engineer.

History

VME began in 1981, when John Staehlin, a senior mechanical engineer at Westinghouse, decided that his skills could be of as much use in helping persons with disabilities as they had been in building radar and communications systems. He met with Dr. Arthur Siebens, of the Johns Hopkins Rehabilitation Medicine Department, developed several of Dr. Siebens's ideas and a few of his own. John's family and friends soon joined him, and in 1982 he formed a non-profit corporation, with a six-person board of directors, mostly family members. By 1984 more than 100 persons, mostly Westinghouse engineers, had joined in to work on approximately 50 projects a year, requested by the several rehabilitation institutions in Maryland. Financial support came from private individuals, clubs, and from Westinghouse. Also in 1984-85, the VME began to get national publicity as an example of what private industry could do. Mr. Staehlin was invited to speak at TRW, LTV, General Dynamics, Martin Marietta, and to the Public Relations Committee of the Aerospace Industries Association. The National Society of Professional Engineers, and several other trade and professional organizations, also began to publicize the VME. He soon had requests to form chapters from several other locations. The Maryland group was reorganized to recognize possibilities of adding chapters, and to expand the Board of Directors to include Dr. Siebens and other engineers and businessmen, and to adopt formal bylaws. Membership grew to almost 250.

After an article in Parade Magazine in 1987, VME received numerous requests for information and assistance. This was a crossroads. The mailing list grew to over 2000 entries. Volunteers would meet us in the hallways of Westinghouse, or write in: "I want to help but you haven't called me." Clients would complain their requests had gone unanswered. We struggled to produce financial reports. We could no longer manage this volunteer organi-

zation with volunteers. So during the fall and winter of 1987 a plan was developed to hire the staff needed to support the ever growing volunteer movement. The first Executive Director, Carole Wayne Forsythe, describes her professional role as "development administrator," i.e., someone who can handle the nuts and bolts of a growing organization. The plan is to raise $3 million in three years, to support the chapters and programs being created.

Organization

The organization being created includes volunteer chapters throughout the country, and, as a result of the recent World Rehabilitation Fund-supported symposium at RESNA on this monograph, affiliates around the world. Most of the U.S. chapters are based in major industries, including aerospace, defense, electronics, and transportation. But several are being started by rehabilitation professionals and disabled persons. Chapter membership include, of course, professional engineers and rehabilitation or medical personnel, but volunteers are also artists, accountants, technicians, lawyers, businessmen, grandmothers and security guards. A chapter is usually connected with approrpiate local organizations: for example, a vocational rehabilitation agency, an Independent Living Center, a United Cerebral Palsy group home, a senior citizens' center, or similar organization.

These volunteers provide direct services, or develop unique, custom-made devices. The chapters will be linked together by an electronic network, to facilitate communication and provision of appropriate information about the state of the art for specific problems. The central office will also establish, in cooperation with the National Society of Professional Engineers, a management and leadership training program.

The second major VME thrust is to establish an Engineering Development Center, to develop affordable "orphan" devices and create opportunities for established or new businesses. It will function as an engineering design firm, creating production prototypes. Licenses for production and distribution of the devices so developed will be given to companies which can demonstrate the lowest possible cost to the ultimate consumer. Most of the ideas developed by the Center will come from the volunteers, but the Center will also draw from NASA, the Veteran's Administration, hospitals and universities, and private inventors.

Other activities of the central office will include:

- an Equipment Loan Center, with a variety of computers or other types of equipment, for use by persons with temporary disabling conditions
- a Computer Skills training center, to provide apprenticeship experience and job coaching
- a Research Center, where researchers on sabbatical from industry participate in basic research and development projects funded with public and private funds

Liability Issues and Risk Management

VME has suffered from America's liability crisis. We began to grow at the time when insurance companies were cancelling insurance for day care centers and gynecologists. The companies in which volunteers work became very concerned about their possible exposure. VME's current organizational development is governed to a large extent by these concerns. Our risk management program has several facets. The corner-stone is a case management system. Each chapter's Project Review and Approval Committee must include at least a Professional Engineer and a Medical or Rehabilitation Professional. We try to keep it simple: minimum requirements are: a record of approval, a project plan, a client participation agreement, and a report. We also have required volunteer orientation. We follow U.S. Food and Drug Administration guidelines for medical devices. With these procedures in place, we have been able to obtain needed insurance coverages. We expect—and hope—that these issues will become less important over time.

Project Challenge

VME members feel that they have a unique contribution to make to the state of the art in rehabilitation, and positive contribution to medical technology. The best engineering talent of the U.S. and other advanced nations is either employed in, has retired from, or is in school being trained for our major industries. This talent is needed to improve the basic quality of life for persons with disabilities, which may eventually include all of us. VME is launching PROJECT CHALLENGE to unleash this engineering talent and mobilize the leaders of our businesses and industries, to make their facilities and resources available. With the backing of the professional engineering organizations and international affiliations, who knows what results may be possible?

Comments by Helga Roth (formerly of NIDRR.)

Eric von Hippel of the Massachusetts Institute of Technology stated in his book *The Sources of Innovation* published by Oxford University Press, that innovations often come from product users who need something different or better.

I could not think of a more powerful argument for the volunteer-client relationship described in the five contributions to this monograph. In the context of REMAP, TAD, MILBAT and VME. The problem solvers, i.e., the engineers and craftsmen from diverse fields and the tinkerers—meet with the disabled person who needs a technical solution to help him/her lead a better life. This person is given a voice, is looked at as a whole person including, if appropriate, in his home and social environment. The "partnership with the disabled individual" which is so rarely implemented becomes a reality in the context of solving a technical problem.

As we all know, one of the banes of our modern existence with all its abundance of communication opportunities is the difficulty of actually linking persons who need something with persons who could meet those needs. Very often we have to have prganizational channels which prepare the way for this linkage so it can acutally happen. This is the function of the voluntary technical aids services described in this monograph. The presentations give us valuable insight into the complexity of creating and maintaining such organizational channels. We should keep in mind the diversity of talents and participants needed: disabled persons with special needs, the *linkers* to the disabled individuals; social workers, OTs, PTs, physicians, educators, welfare officials, other members of the rehabilitation community; and the doers: engineers, craftsmen, designers. As has been pointed out repeatedly there must be a balance between referrals of cases and available talent and resources. Volunteers must be kept busy and engaged so as not to lose interest and drift away. But overdemand must be avoided so that clients and their intermediaries do not get impatient and disillusioned.

There are two tried and proven approaches to create a national-level organizational structure: bottom-up and top-down. Bottom-up is the grass roots approach. Orgtanizations devoted to a common cause or purpose have sprung up in many localities and finally join together and create a "national head office" as a communication link, a PR tool to present a common image, or for any of the other organizational or administrative purposes which benefit the local entities. Top-down is the path of a successful organization which decides and finds the wherewithall to spread its mission to sites across the nation, starting with a regional network which then creates local affiliates.

Since voluntary technical aids services exist already in the US, the approach to multiply and strengthen them will necessarily be a bottom-up approach. Mr. Tobias has spelled out some important do's and dont's for such an effort, and Carol Forsythe has described well the development and organi-

zation of VME. I only want to add that a potential *national headquarter* has to sell its existence to the locals. Tobias has mentioned two powerful offers: liability insurance and a national level database. With the cornucopia of existing commercially available equipment with which is difficult to keep abreast, the potential vast number of one-of-a-kind technical solutions which are rarely documented, the advantages of a central well-organized information operation is obvious. Again such an information operation can build on and use what is already available for commercially produced aids such as ABLEDATA and JAN and perform the search services for local affiliates on request.

To get documentation for individually designed aids is an incredibly difficult task. The REMAP approach makes good sense. To get liability coverage a project must be registered with the local panel and some description forwarded to national headquarters. A modest but promising beginning.

Certainly there is no dearth of potential volunteers. America is a nation of "Mr. Fixits" and tinkerers. Somebody must take the trouble to find them, recruit them and keep them happy. The challenge of being asked to create something "new" and at the same time improve the life of a person is a wonderful recruitment tool.

The US has a fine tradition of volunteer administration and a cadre of professionals in this field who can give advice and support. There is no question in my mind that a voluntary technical aids service built on what is already in existence can make a significant contribution to the lives of disabled individuals.

COMMENTS FROM THE HILL: Andrea L. Solarz, Ph.D., Congressional Science Fellow U.S. Senate Subcommittee on the Handicapped Washington, D.C.

These papers from several countries describe various strategies for providing assistive technology services and devices using volunteers to complement the efforts of traditional programs. As the authors point out, most societies simply do not provide enough resources to meet all of the needs of people with disabilities.

It is clear that assistive technology can play an important role—across all major life activities and throughout the life span—in the lives of individuals with varying types of disabilities, and that the possibilities for using assistive technology to change the lives of people with disabilities are immense. There is substantial evidence that providing assistive technology devices and services to people with disabilities is cost-effective, allowing these individuals to live more independently and productively. However, while a substantial number of assistive technology devices already exist, transfer to the special, long-term needs of persons with disabilities has been slow, sporadic, and uneven.

There are a number of barriers to the dissemination of needed assistive technology to persons with disabilities. One of the most significant barriers to gaining access to assistive technology devices and services is lack of funding. For many persons with disabilities, the burden of paying for often costly assistive technology falls on them and their families. In the United States, people with disabilities are often denied payment for these services under Federal health insurance programs because these programs are designed to provide assistance for acute medical problems rather than the chronic problems faced by people with disabilities.

Another key problem is the lack of trained personnel to deliver assistive technology services. Because the provision of assistive technology services involves a unique combination of products, services, training, and evaluation, it requires expertise across a broad range of areas. In general, there is a lack of professional preparation, both preservice and inservice, in the appropriate delivery of these services.

There is also a lack of available information about the potential of technology, and dissemination of information is not coordinated. It is critical that information be available, not only to the consumer of assistive technology, but to his or her family, people who work for public or private entities that have contact with individuals with disabilities, employers, and others. The MILBAT information center in Israel, described in the paper by Daniel Barak, presents one option for making information about assistive technology devices widely available and accessible to a broad range of consumers.

The current lack of coordination among most existing State human service programs, and among these programs and private agencies, is

another significant barrier to the development of comprehensive programs of technology-related assistance. Coordination between programs is particularly crucial when individuals with disabilities make transitions between programs; for example when a young adult leaves the education system and begins receiving vocational rehabilitation services. The need for technology does not significantly change as a person engages in different activities, such as school, work, or independent living. Consequently, it is important that technology be as transportable as possible.

Coordination is also lacking between the public and private sectors. To date, the private sector has been primarily responsible for the few innovations in devices, techniques, and services that are currently available. Unfortunately, because of limited commercial markets, the private sector lacks the incentive to become involved in the development and distribution of technology devices to meet the needs of people with disabilities.

Finally, most State systems simply lack the capacity to provide the necessary technology-related assistance. They do not have the means to carry out the planning, coordination, development, marketing, or training necessary to utilize technology effectively.

This year, the Congress passed legislation to address these barriers to access to assistive technology services and devices; the "Technology-Related Assistance for Individuals with Disabilities Act of 1988." Title I of the bill establishes a program of grants to States to develop and implement programs of technology-related assistance that are consumer-responsive, comprehensive, and statewide. It is anticipated that these grants will serve as a catalyst for States to: (1) comprehensively and systematically review current policies, practices, and procedures used by public and private entities relating to the provision of and payment for assistive technology devices and services; and (2) develop and implement comprehensive strategies for expanding and improving opportunities for individuals of varying ages and types of disabilities to obtain high quality assistive technology devices and services appropriate across all major life activities. Initially, up to ten States will be funded; eventually, it is anticipated that funding will be available for all States to participate in the program.

The legislation recognizes that States differ in their resources, delivery systems, organization, and population needs. Thus, States are given substantial flexibility to capitalize on their own unique strengths in establishing statewide programs. For some States, this may mean developing or integrating volunteer programs into their existing systems of service delivery to provide more coordinated and comprehensive approaches to providing technology-related assistance to people with disabilities. For example, Australia's Technical Aid to the Disabled (TAD) organization described in the paper by George Winston could provide a useful model for some States wishing to supplement traditional State programs for providing assistive technology services and devices.

Title II of the legislation focuses on the role of the Federal Government in providing assistive technology devices and services to individuals with disabilities. Among other things, it calls for a study of the financing of assistive technology devices and services, and a study of the feasibility and desirability of establishing a national information and programmatic referral network on technology-related assistance. It also supports training and public awareness grants to increase the knowledge and effective use of assistive technology devices and services, and funds various demonstration and innovation projects.

This new legislation is designed to encourage the development of creative approaches to providing assistive technology devices and services to individuals with disabilities. Its focus on coordination between the private and public sectors clearly supports the involvement of volunteers, both professional and para-professional, in the development of programs and in the provision of services.

August 1988

APPENDIX

On June 26, 1988, at the RESNA/ICAART Conference held in Montreal, the World Rehabilitation Fund and the World Institute on Disability in conjunction with RESNA as arranged by Jim Tobias, Chair of RESNA's Special Interest Group (S.I.G.) on service delivery, convened the symposium on Volunteer Rehabilitation Technology. *Jim Tobias* chaired both the morning and the afternoon sessions. Featured in the morning were *Percy Hammond* and *George Winston*, who described their respective volunteer rehabilitation technology programs and efforts. There was some discussion following the presentations. In the afternoon, *Dan Barak* talked about MILBAT and some of the "one-off" solutions the Israeli group has come up with. Following Mr. Barak's presentation, several U.S. respondents spoke up with comments and questions. Among the invited respondents were: *Carole Forsythe* of VME (her paper appears in another section of this monograph), *Vic Ransom* of Telephone Pioneers, *Alexandra Enders* and *Ken Reebs* of the Electronics Industries Foundation, *Ralph Hotchkiss*, *Jim Tobias* and *Martin Marshall*, of REMAP.

What follows are some edited excerpts of the responses and discussion which attempts to convey the flavor of a very dynamic interaction.

A.M. Session

Initially, a three-part question was raised from the audience by Colin McLaurin for Mr. Hammond and Mr. Winston:

McLaurin: Usually retired engineers doing this kind of volunteer work want to do something they want to do and something "original." However, the volunteer might not be aware of the state of the art. Another problem is that if "I" the volunteer build something original, how will someone else be able to repair it, if it is not "simple." Also, as a volunteer, I may need time for two or three "tries." How does this affect delivery time?

Hammond: REMAP has panels of engineers so 6 or 7 sit around a table and look over the various projects. Sometimes, but not always, the right volunteer gets the right assignment. Volunteers seem to be strongly motivated to do the job for its own sake or for the sake of the person who wants it done, rather than to refuse it because it is not something they feel they specialize in. Naturally if the job requires electronics, an electronics shop will be needed. Regarding your question on delivery time, there can be a problem of delivery time, especially, for example, if the project is assigned to a university chap who turns it over to a student engineer who has nine months to carry out a student project. Other projects can drag on for various reasons.

The disabled person probably accepts it on the grounds that after all they are doing it on their own time.

Regarding your question about post-delivery service: yes, there are more and more high or medium tech solutions being used and a support system is definitely needed. If the volunteer is in the vicinity of the recipient of the solution, there is no problem. If he isn't, it's up to the chairman (of the panel) to make sure that someone else is around to do repairs. However, there is not doubt that this is a problem. For example, I took on a job myself because it was just down the road. A disabled child had a wing chair made by some other panel imported into my district. I took on the job of maintaining it. And then the family moved to another district so I had to chase around, find an engineer in another panel who would maintain it. So the problem is not forgotten about. It is usually picked up.

Winston: I think that everything Percy said about the panels is true for our (TAD) regional chapters, but in the big city group we operate rather differently. We've developed a situation where we really know what's going to excite certain people. So having 200 odd people in the one group we can allocate projects in such a way that people are going to be really in love with the project. As for delays, we've managed to gradually improve the situation from probably an average duration of 6 to 9 months down to where practically all our projects are done under three months and a lot of them are done in one or two weeks. The repairs of high tech equipment is a problem.

Each electronic project in a capital city at least must include servicing information when it is delivered, sometimes even by laminating a schematic to the device itself. Usually, our volunteers are tied into the servicing. It has not become a big problem yet, but we are aware it could.

Questioner: I wonder about the "occasional" volunteer.

Winston: This is a real difficulty in the electronics area. We have trouble recruiting people who are right up to date because the people who are "current" are usually working 60 hours a week, whereas those who have the time to volunteer are retired, and therefore simply are not up to date. However, I still think it's better to do something than to do nothing about the problem.

Enders: Also, with regard to repairs of the high tech stuff, I think it's similar to considering a product that comes out of the Rehab. Engineering Centers, any time something is developed when there is no support.

McLaurin: I think a really more important point is being raised here, i.e., how do you establish a national system which is state of the art? Obviously we don't have that, and obviously there is a place for the less-than-perfect solutions. Looking ahead, however, I don't see volunteers replacing the kind of system that is able to handle the problem of technology for disabled people correctly. I think the more we can do to encourage the holistic, long-range view, the better. You see, nowadays, it is possible to build custom items using automated systems. Eyeglass production is one example.

You can go in and have your eyes examined and walk out with custom lenses ground in an hour. To expand that type of system into other areas of technology won't happen overnight. However, it is a long-range national and international scheme that should be considered and worked toward.

Hammond: I want to make a point. I think REMAP people generally would be quite happy if they worked themselves out of a job. In other words, they aren't dedicated to the self-perpetuation of this volunteer activity. Where at the moment it is filling a need, in 20 years time it might not be. As an example of that I want to mention Newcastle, where there is a REMAP center which was very active. It was taken over by a professional rehabilitation engineer workshop and I think everybody was quite pleased so I think that's the attitude we've got.

P.M. Session U.S. Respondents

Ransom: Jim and I work together and a long time ago he told me he was going to have this session and he was going to bring people from all over the world involved in rehabilitation and engineering and he told me "now Victor I want you to talk about the Pioneers," so I'm going to tell you a little bit about what the Pioneers are because I suspect you don't know. The Pioneers are a huge organization—initially it was a Bell System service organization. It was created for fellowship and for service. There are 500,000 people in the Pioneers, most of whom belong because they have stayed in the Bell System long enough. Although a lot of the long-time people don't volunteer for anything, what they do is a fair amount of fundraising within the organization so that they are able to get money together. And over the years quite remarkable things have been done and in a wide range of areas. There is in each chapter, and there are chapters associated with the various telephone companies, a professional person. That person is spread very thinly over a whole variety of activities from Meals on Wheels to serving in nursing homes to a small group to do rehab. engineering. The message I'd like to give is that they do very many good things. In fact the corporate management is very proud of the Telephone Pioneers. How do I relate to this? Well, I worked for Bell Laboratories for about 30 years. I passed the magic age and I kept expecting somebody to ask me to do something. Nobody did. Then the Telephone Pioneers management asked me to be vice president, and I was vice president for a while trying to figure out what everybody else was doing. I was in the Bell Labs team and then I moved into a new corporation that had been formed to support the operating companies—Bellcore. But one of the finest things that I thought was happening in the corporation, particularly in these high tech groups was that a handful of people were doing what I now know is rehabilitation technology. They were helping people with various communication aids with computer access and environmental controls. When I fulfilled my obligations as vice president in the Pioneers I thought I would then start to work in this area. And here's where I think we need help

and why I'd like to think I'm responding to the messages I've gotten here. I think that we don't—as Pioneers—even know each other and what we are doing. I'm in a group in my company, in my segment and we do something and I don't know what the other Pioneers are doing. Once a year they do publish a book that shows projects but I don't even know who does these things. Now I think that's a serious weakness but an even more serious concern I have is that we as engineers, who decide that we are going to help a neighbor or someone who has a problem, don't know anything about the rehabilitation industry. We don't know what products are being produced. Sadly, we tend to reinvent the wheel. We do some marvelous things but on the other hand we're not being nearly as productive as I think we should be. And what I'm glad to hear and what I'm delighted to see is the VME starting and what I hope to do with help from people like Jim Tobias is to start tying this huge Pioneer network together to make us more effective. If I have any message for the audience and those who are looking at volunteers and asking how they can relate it is that we have a tremendous resource in our engineering talent. We have a lot of sweet people who want to help, but what we lack is the organization such as that which we have heard described in reference to England and Australia.

Tobias: I am going to step out of my role as chair of this session for a minute to talk about my organization, the Rehabilitation Engineering Volunteer Network, which is a small volunteer group based in New Jersey. We see ourselves as coming out of the rehabilitation community. All of our chapters are at rehabilitation sites and most of the people in our chapters are rehabilitation professionals. And we see ourselves as recruiting technical volunteers rather than as technical people going out and trying to find the clinical links. The most relevant thing that I can talk about today is a grant that we received from the Easter Seal Research Foundation to study the use of technical volunteers in rehabilitation in the United States. It is a grant to do a census of what's going on out there. We are finding some surprising things although it is very early on in our research. And as you might think, there are some easily identified groups working in this field. Certainly VME and the Pioneers are the two biggest and most ambitiousihuprojects. But other projects may have only two people working anonymously in a shop building on a project and would be more than happy to continue that work if they knew that there was someone else who might benefit from their services. We're finding many different types of organizational frameworks in between, finding people who are working in philanthropic organizations, people who are working out of industrial settings, people who are working within professional organizations, such as the Society of Industrial Engineers. And their products are all different as well. Some concentrate only on one of a kind, some have developed sort of a cookbook approach where they'll give you the parts and the part layout and even the artwork for the circuit board. So what we are finding is a full range of things that are already being done in the United

States. We are going to ask them questions about how they operate and how they do case management and how they deal with the issue of what's already available in the "rehabilitation armamentarium". We want to know if there are any kinds of central functions that they could see performed by a coordinating bureau. Not an umbrella agency that is going to try to subsume them; but rather something that can provide some support services for them such as a data base of completed projects. It would be a place where we would have all of the projects that volunteers have completed with access to them even if it's only to look at them and say, "I can do better than that." You know that is something that volunteers are somewhat interested in as well. And perhaps Dudley Childress who is also of the Easter Seal Research Foundation can say some more about the grant and possible future plans that the foundation has for the idea.

Childress: One of the reasons we were interested in this idea was that we saw the possibilities for the Easter Seal Societies. These already exist in the United States, in all the states, and they have comprehensive rehabilitation services. We thought there was an opportunity if volunteers could be coupled with the Easter Seal Societies to provide services where services are not being provided now. So there's already an organization here. There's already a national group; there's already fundraising: there's already computers, and I visualize the possibility of integrating a volunteer system with an existing organization so you don't have to create something completely new. I don't know whether that would work or not but at any rate Jim Tobias is finding out what is going on and maybe learning what's possible to do. I'm on the United Cerebral Palsy Association Research Board also, so I'm not necessarily suggesting that Easter Seal would be the only organization, but since it is not focused on one disability, I thought it had a chance of coupling together with volunteer groups.

Marshall: I was the national organizer of REMAP for some time. I'm currently editor of the REMAP Yearbook. When I started becoming interested in REMAP, I of course quickly was confronted with that "appalling" thought of reinventing the wheel. The fact is that panels in Britain—there are 90 of them—are not prevented from looking at a problem which has been presented before. They may not even know it's been presented before. I am reminded that I suppose for 5 of the last 7 years a panel—a different panel has produced a new solution to an eye dropper. A very simple thing but they are better and better and even better and still better eyedroppers. So don't be frightened at any stage that somebody is reinventing the wheel. We've got to look at this from the point of view of a volunteer engineer, particularly a retired engineer. We can get him hooked because he's having fun. And if you deluge him with paper which shows somebody else has been working on the same exercise, and say, "Lay off it," he loses his reason for being active in the panel.

There was some comment about the difference between a "one-off"

solution and mass production. About 6 years ago a number of interested parties in Britain in this field settled down to see what was available, what could be done about small-batch production. A particular device was effective and one quickly led to a demand for 50. And sadly we found it extremely difficult to meet that situation. It is a gap—it is a gap that exists in industry. We jumped from pilot production to mass production, and I assure you it exists in this field. There is quite a leap from a one-or-two-off to suggesting that volunteers can produce a fairly large batch. They are not interested. They want to do something original. They are not terribly interested in copying. You have to face up to that fact, and plan your volunteer efforts around the thought that your volunteers have to be satisfied. Otherwise they won't continue to be volunteers.

Reeb: I'm with the Electronic Industries Foundation. I was asked to address the issue of the relationship between one-of-a-kind solutions and commercial products. I carefully read the articles and I was very pleased to see that each organization represented has some fairly rigorous policy related to exploring alternatives that may be available commercially before embarking on projects that are more highly customized. Jim Tobias pointed out in his article that REMAP does have a formal policy about looking at commercial products, but that it's not always adhered to.

I think that's a fundamental struggle that these organizations will continue to wrestle with. There's an inherent interest on the part of the volunteers to gain some sort of fulfillment out of the work that they do. But at the same time, it is very important that the sorts of policies that we see in these organizations related to reliance on commercial products first and foremost are maintained as much as they can be within that struggle. The motivation that Jim points out in some cases had to do with the cost of a commercial product, which might be too expensive for a particular client. I would argue that in that case it is not a technical problem and should not be dealt with technically. It is a payment problem and if the creativity that the volunteers in these organizations demonstrate technically could be channeled in creative ways to help those persons afford what is available, I would encourage that those channels be pursued.

The other motivating factor that Jim points out is that in some cases someone wants to prove a point: "I can do a better job than what is on the market." My argument to that would be: Don't compare apples with oranges. A commercial product is not just a physical object. It includes the marketing, the fact that product is available in many locations and that there is service and maintenance available*. There are all sorts of elements that are packaged into that commercial product that are not directly comparable to the item that's being developed or customized. You have to recognize the overall

*Ask Ken Reeb for his article that discusses this issue fully.

system that commercial suppliers, rehab professionals and volunteers are all in the same business and should understand their respective and interdependent roles.

Hotchkiss: I've gotten to know a fair number of disabled people and rehab. people in third world countries and it's truer there than it is here that most things are done by volunteers. There is no funding mechanism for most devices that are built, or work that's done for and with disabled people. A good example is groups that have set up their own wheelchair factoriess. The jigs and fixtures in the development of wheelchairs for low-cost production were all done by retired tool and die makers down in Paraguay—the initial work. More work has been done by retired machinists in the Philippines. And on a one-to-one basis I run into more good examples of howmithere are volunteers out there doing what's needed. There is no other way it gets done. What they need is input from the rest of the world. They are reinventing a lot of wheels only because they don't have information about how it's already been done.

As for the points made a moment ago about batch production: in the third world batch production is cost-effective. Batches as small as 5 or 10 are done, exported and sold in competition with mass produced items in this country, and they beat them both on cost and quality. So designs that are suitable for low scale production will fit in much more effectively in many third world countries than they do here and become a more lasting part of the rehabilitation technology there. The information, I feel, is often disseminatedmore effectively through organizations of disabled people. There's already quite a large and well-established network of activist disabled organizations: Disabled People International is the primary communicating group among them. Jim Tobias, for example, learned how to be a good rehab. engineer by working for an activist organization, the Center for Independent Living in Berkeley making custom items for people. I think you'd agree that that's one of the best ways to get stuff out because people often don't. What we need to do is disseminate as much as possible.

Van Etten: I'm a rehabilitation engineer in Rochester, New York in private practice. I'm not working through a center, so I share some of the concerns of the volunteer and can understand that there is protection in a center.

One of the issues that I'd like to bring up is product liability insurance and professional liability insurance that would be needed for any type of American volunteer system. If you are going to expect these people to volunteer their time, the question that follows is: are they also willing to volunteer the risk? I think we have to ask ourselves, "Is there an insurance mechanism, a way not only for the volunteer individuals to tap into, but also for any practitioner that is outside the shelter of some type of center." I advocate that RESNA come up with a solution in that regard because I don't think a program like this is really going to take off until that one barrier is overcome.

The second thing has to do with the time element. Whenever you are working through an agency or organization, there is high expectation that you have results, but also that you do it in a timely manner. In my practice what I try to do is tell them how long I anticipate the process will take. This varies depending on my load at a particular time. What I would like to recommend to any volunteer organization is that they have some type of time structure and that time structure is well-recognized by the client as well as by the engineers or volunteers that are working with it. And if that can be shortened by having more volunteers you will probably come out better in the long run.

The last thing—and I think this is very important—is continuity. One of the reasons my practice is working is that I'm just not making recommendations, leaving it up to everyone else to take it from there. I'm there to help out in the installation, if need be, in the training and the use of the equipment, and, if it breaks down at a later time, guess who gets called? I do. So you become very familiar with the equipment and the vendors that you might be working with and using the equipment. Again the recommendation I would make to a volunteer group is that—when they do a prototype or one-of-a-kind design that that design is well documented as to how it was constructed. Any preliminary or final designs are reproduced and kept in two different locations. A second recommendation: that more than one the designer is involved in the final stages of knowing how it was put together. And the reason I say this is because there is going to be a certain amount of turnover. Volunteers may decide to move or retire, and at a later time, if the equipment needs repair, there must be someone around who is familiar with it.

Enders: Do you think volunteers will interfere with the work of professional rehabilitation engineers?

Van Etten: I do have a concern. If a volunteer involved in this work, begins to see himself as a rehab engineer, I call that the "jackrabbit" effect which means that a volunteer practices in the rehab field for a year or so as an engineer and he does a couple of things and he does fairly well. Right away he proclaims himself a "rehab engineer." What he doesn't understand is that those who have been in the field for a while realize that it gets more and more complex, and it takes a lot of experience to really get to know how to work with clients, how to work with the system and with counselors. There are many different aspects to it. I would say, as far as my experience, it is maybe 10% engineering, 10% that is critical, but the rest is learning to be a good people-oriented person, learning how to run a business and to keep yourself on a time line. Over the years someone can acquire the information and understanding. If we're working together during those periods of time, I feel he would be considered a colleague, and I hope he would consider me a colleague and there is more than enough work out there for both of us to handle. I'm not an expert in everything. If I'm an electrical engineer, I have limitations on mechanical engineering. And I'd love to know that there's a

volunteer group out there that I can ask questions of. But the solution may not get through the funding sources. If I propose a project to volunteers andidithey're willing to take it on, I'm one step ahead of the game. And that's great.

Enders: Now I'm going to be the curmudgeon. And I think I probably planted the seed for some of this. The project I'm working on is funded by the National Institute on Disability and Rehabilitation Research, to look at rehab. technology service delivery in the U.S. One of the things that our grant was to do was to look at the role of volunteers in the service delivery system. I'm really pleased with this—I can't believe this is coming together. This is great. But there are a lot of concerns haven't been voiced here. Maybe some of them are conceptual and philosophical. It is much nicer to talk about the wonderful spirit and the wonderful project, but we really do need to ask the question: how does volunteering fit into the American system of technology service delivery.

I have wondered, 25 years ago when REMAP started in England, if we had a similar system starting in this country, would we have service delivery the way we have it today in the states? I have wondered if volunteers had been available in the U.S. at the same level would that have impeded our service delivery process and the pressures that have just recently brought about the beginnings of a coordinated service delivery system? I'd especially like Dudley Childress to help answer this because very often when I've talked to the folks doing volunteer service delivery here in this country, it looks a lot like what I think it looked like 20 years ago when all you folks in rehab. engineering research were trying to figure out how you were going to get your research out into the community and how you were going to get these things into the disabled people's hands. Does the existence of a volunteer system impede the development of regular services? Why I think it's important is because I think—and we aren't quite ready as a country to say this—that people with disabilities have a right for technological support that they need. And if it's approached charitably and altruistically, it is not viewed as a right.I also came out of the Center for Independent Living in Berkeley and had my training in advocacy from that movement. I'm very concerned that technology is going to be viewed as a privilege rather than a right.

Forsythe: I think the American system is going to take care of that. And I think a strong consumer movement from the centers for independent living or other consumer groups is growing up and is going to make use of their political clout. They're using their political clout to create within the state and federal governments the mechanisms to make sure they get that technology. With respect to the marketplace, the economic system is such that anything that any volunteer group or any other group invents, if it's got a market there is going to be someone there swooping it up. That's going to get it into the commercial mainstream, funded through the system to get to people where it's needed. And the more demand there is, then the lower the price is going to be.

Ransom: Can I just make a 30-second comment? I think that the volunteer can become a part of the advocacy group rather than part of the enemy. I think that what we as volunteers learn in this process is how much needs to be done. We're shocked by the ridiculous funding arrangements we have in this country today.

Winston: Thank you. I don't want to presume to comment too much on the U.S. but in Australia I was on a national committee for rehabilitation engineering for about five years, and there were two international conferences held to stimulate interest in rehabilitation engineering and to try and create some kind of service delivery. Nothing happened in the end. We pushed andihuwe shoved and we screamed and we kicked and mainly it was a problem of government funding and it didn't happen so volunteers are actually stepping into and filling a vacuum. I have a feeling that very often it's the vacuum that draws us in to deliver the services that aren't being delivered.

McPhail: I coordinate an applied technology lab at Southwestern Regional Center in Ontario. We serve 587 developmentally handicapped adults. And in '83, I was asked to look at the application in technology without any staff and without any budget in the residential setting where we didn't have any technical support. So as was addressed by our friend from Australia, we had the vacuum and we needed the technical support and I went out into the community looking for that support. Now I can tell you about 7000 hours of volunteer time that has been given to the clients at Southwestern Regional Center since '83 or since January of '84. I can tell you about people that helped us raise money as volunteers. I can talk about high school, college, university students that have been involved in helping us with projects. I can talk about young mothers with children that have come in and helped write software and so on for our clients. I can talk about electrical engineers that work for Bendix. They may be the leaders in automation technology and industry and as I went through that plant I identified some of the sensors that they were using on their line, noting I could use that with "my Jane", with "my John." How about coming out and seeing my clients? Then we have client identification and they started to provide that service. In fact, I have two young engineers that have given us nearly $60,000 worth of expertise and just this last month they received a provincial award for their volunteering with developmentally handicapped adults. Last week the Canadian Broadcast Corporation called me because I had been nominated for an award for innovation in technology. I'm a minister of religion. I'm not an engineer. We are taking volunteers, introducing them to clients, helping them meet the need. The vacuum is there and it is building. Now because of that build-up, there is a lot of pressure on our provincial government to start funding programs like this. Because of that there are engineers who are coming forward and saying we now want to address those needs. And so I'm proposing to you that there's a tremendous need for volunteers. My role is to

help to facilitate it; to go out and introduce potential volunteers to this population, and tell them how their expertise can be used. I believe also that in introducing them I have to interpret to them the benefits—the two guys for instance over at Bendix that have given us $60,000 worth of time—they are involved in the air bag program right now for Ford. That's challenging to them. But at the same time they wanted to do something for a real human being. By introducing them to our clients and letting them come up with some technical solutions to some problems, they, too, were and are able to get some of their own humanitarian needs met.

Enders: I would like to get back to this other issue. If we are going to figure out where the volunteers fit into the system we're going to have to look at what the impact on the system is. I want to give you a little anecdote. When we were at Berkeley, we had the paratransit system. We ran a fleet of vans, but we did not believe there should be separate transportation systems. AT the same time that CIL was running a paratransit system itself with city contracts, it was suing the local transit authority to make the buses accessible.

One approach says you provide services because nothing is there. And the other one said you go out and do advocacy work and the advocacy will get you the kind of support that provides services. And so I don't see this as an either/or approach. Sometimes both are needed at the same time. Andihiwhat's interesting about your hybrid approach and I mean you're running both sides of this. You know you are playing with both sides of the issue if it's important to fill the vacuum. We shouldn't say that until the system is delivering wonderful services disabled people shouldn't get the things they need. But at the same time we have to attempt to impact on the system.

My personal advice is we have to work at both approaches at the same time. We get calls from people all over the country saying "please help me." They don't know how to get local rehab. technology services and if they did they might not know how to get the funding for it. And the inclination when one is in that kind of role is to try and help rather than to try and change the system. So what kind of support would volunteers need from systems changers? What kind of coalitions can you build at the same time so neither one of you is working in isolation, so while you are filling the vacuum, they are changing the system? And you are all doing it together. That would be the kind of approach I would take.

Tobias: I agree with you, Alexandra, that that's a problem. However, it has never been my experience that a volunteer who is actually working on something for a client doesn't eventually come to the realization when the 20th client comes to the door that there is a systemic problem here that we have to deal with. I think that's exactly what happened to community activists in the '60s when they were working in small storefronts and they realized there is a bigger problem that needs to be addressed. So, I agree with

Vic that there is a way, in fact, of implementing that kind of social change to encourage a greater exposure of people to the problem.

As to your other point, we can't as professionals declare that there is a right to something that occurs when enough people come to the realization, "Hey, why doesn't everyone have one of these things." It's general social exposure to these kinds of expectations. I think that the more equipment that there is out there, the higher the level of expectations there will be in society in general. So in answer to your original question, Alexandra, I think if we had a REMAP 25 years ago our service delivery system would be better than it is now simply because there'd be a lot more devices out there and more people would want them and the system would have been impacted on. Also those volunteer organizations would have realized that their role was more than rehabilitation technology but also included advocacy.

Enders: In media coverage, often when they have reported on the wonderful things being done they are not asking: "Why isn't everybody getting this equipment through the Ministry or whatever?" How often do they make that connection? They are simply saying what wonderful things you are doing, and assuming that there is no system to be impacted on. This is what propels more and more people into the volunteering.

Ransom: I think you are making a very important point. They get politicized by coming into the experience. As engineers, we are generally very bad politicians. We shy away from it. We want to do something "useful." You discover that you go into the situation and you say well why don't they buy the X or the Y and you discover that Medicaid doesn't pay for it and you are horrified. You can't believe that. You hear, "Well, it's not medically indicated.... It's quality of life, so we won't pay for it." Things like that upset this placid engineer who is not normally political. I think there is no point in beating up the engineers because they aren't changing the system. We all have to start pushing on this society to say it's ridiculous that we are not providing quality of life technology because it can in fact lower the cost of providing care ultimately.

Hammond: Can I make a note on what I think is an ethical situation? The important thing is to deliver the help that's needed. In the case of the UK system it's much simpler than in the U.S. RADAR (Royal Association for Disability and Rehabilitation) for instance has a lot of lobbies in government, so RADAR can lobby the government and push for the sort of things the government ought to be doing for disabled people while the volunteers can do their jobs on behalf of disabled persons. So perhaps it is simpler for us in the U.K.

Bianco: I come from one of the 50 states in the United States, Pennsylvania, which has no system for the delivery of rehabilitation technology services. The state has admitted that in a document published in 1986. It indicated that although it spent approximately half a million dollars it provided services,but it did not have a rationale for the delivery of those

services. This speaks to the fact that there's disparity between the states. Here we're caught in a discussion about the system and how services ought to be delivered thorugh a system and then how volunteers creating their own system as you describe it would in fact fit within a context in which there is no system. My own experiences is in the provision of rehabilitation services. Let me say that in the defined services that our facilities offer we do not describe a service called rehabilitation technology. We describe physical therapy and occupational therapy, and speech therapy and recreational therapy and we do that because in the States it's been my experience that form follows finance. That's how a system is developed. So here we have a situation where in the U.S. we really don't have a system as such. We have competing forces and then we have volunteers. And let me pose to you that perhaps we should be thinking about two different matters. One is the development of a rational system of service delivery and that can be affected by advocating for financing services. The Office of Technology Assessmednt back in 1982, I believe, published a report and that was the sum and substance of it. They said that we have created so many different kinds of providers and we have distinct systems for the delivery of care, for example: Rehabilitation and Medicare. Then we have another matter which is the integration of disabled people into society and how people who are not disabled treat disabled people and relate to disabled people. And it would seem to me that volunteerism has a great deal to do for that. Perhaps what volunteerism should do—and I resist saying what other folks should do, but perhaps it would be more fruitful if volunteerism were consdiered as a tremendous resource in establishing how neighbor treats neighbor and community accepts disabled people, rather than to focus upon the other matters of how volunteers should effectively pursue the financing of services and the delivery of services. It seems the merit of the discussion for me has been to show how earnest individuals can respond to a situation and marshall resources and their wit and ingenuity to help other people, and I think this merits focussing on.

Steve Tremblay: Looking at this from the consumer perspective, I don't think that having volunteers available is going to hurt us in any way in trying or making the gains that we need to make. Those resources have always been a part of this country and other countries in the world. If anything, I think they will add to the value of what we gain from that so we welcome the volunteers aboard and their solutions as well. But it really does have to be spearheaded by consumers and over the issue of whether it's a right or something that's not a right, that's really what disabled people have to decide for themselves and organize for.

Forsythe: I'm going to challenge the rehabilitation professionals to use volunteers. This country has been built a lot on volunteerism. Museums use volunteers. Symphonies use volunteers. Volunteerism is for everybody.

Ransome: We are just getting sensitized to realize there is a political issue. But the worst thing that can happen is to have the groups tearing at each other, and the professionals putting down the volunteers.

Enders: And the volunteers putting down each other.

Ransom: That's another way to destroy it. The message is that the service isn't being delivered and why isn't it? Because the society isn't recognizing that there's a problem, that there are solutions coming on board and that all of us ought to be working together on solutions to the problems.

Enders: I think one of my favorite lines out of the whole meeting was what you (to Barak) were saying at the beginning today about when you first started with the silver eye shadow and the laser, that you had just assumed that people who were involved with that person would have tried all simpler possibilities. That is just so poignant to me, when you admit that you had assumed that you were being called just to do the top-end technical work and realized that no one else had thought of the other possible solutions. For the most part my colleagues haven't been trained to do those things. And when you come in, I think you look at the rehab. folks as really being experts on a lot of things and giving you direction. We're not going to admit we don't know how to give you direction. I was working at CIL and Jim (Tobias) came in as a volunteer. And the other OT and I thought up this device for this person who was in a nursing home who had MS. And then we wanted Jim to implement it. Real typical interaction in this country between OTs and technical people, right? I have this wonderful Rube Goldberg device thought up. Now, will you please build it for me." And he took one look at it and he looked at it again, trying to be polite, but very disdainful. He said, "Why don't you just use a tongue activated microswitch?" And I said, "I don't even know what a tongue-activated microswitch is." It's a real miscommunication about the levels of technical expertise. He just assumed we should know about microswitches in 1975. And we've learned and he's learned.

Barak: In many cases I hear about "we the consumers" and "you the volunteers"—I disagree completely with this attitude. I don't think that I have to break my leg in order to be qualified. From the other point of view, as I told you the head of MILBAT is a lady in a wheelchair. I didn't ask her to come in and work because she was in a wheelchair, but because she is a good person for the job. And I don't want handicapped people to discriminate against me. Or discriminate against themselves. Let us work out whatever it is that is needed and each one work within his capacity. If some handicapped person can provide me with another outlook on the problem, I would welcome it.

Mary Holt: You've talked a long time about problems in the U.S. and that's very nice but you know this is an international meeting and I could put in a few words as sort of a volunteer from a third world country. I work with a rehabilitation center of about 300 individuals in Korea. We have a long term care facility. But you know this is my first time in a meeting like this. I've been working in rehabilitation work as a nurse for more than 20 years. I think nobody in Korea heard about this meeting and you realize the Para-Olympics are going to be there in October (1988) and do you realize they don't have any

disabled persons on their committees, and never thought of it, and do you realize they don't have any transportation for people in wheelchairs there. It is strange to me to hear you complaining about the lack of services and funding in America. You know, there is almost nothing in third world countries. Volunteers are often misused in third world countries. There is a government facility that has two or three times our funding with a similar population. And the children are so much more poorly cared for. And they refuse to let the volunteers to go there. But it is really quite important now because of the Para-Olympics. The Para-Olympics are doing so much for Korea. I just want to open your eyes to some of the things that volunteers could be doing in third world countries. But it's frustrating seeing so little development in areas that I feel are quite important like public transportation, even for our guests that are coming. Five thousand people are coming to Korea and I suppose it will be more than 5,000, as they have wives and husbands in wheelchairs, too. You can get a wheelchair that doesn't fold into a taxi. Taxis are about the only transportation available at present for wheelchairs. A little action now would do something for the Olympics.

List of Participants on Tape

Below is a list of the symposia participants and their affiliations whose remarks are recorded in the preceding material:

Percy Hammond - REMAP, England
Martin Marshall - REMAP, England
George Winston - TAD, Australia
Dan Barak - MILBAT, Israel
Jim Tobias - REV and Bellcore, Morristown, New Jersey
Colin McLaurin - University of Virginia, Charlottesville, VA
Dudley Childress - Northwestern University, Chicago, IL
Carole Wayne Forsythe - VME, Baltimore, MD
Vic Ransom - Telephone Pioneers, New Jersey
Ralph Hotchkiss - San Francisco State University
Steve Tremblay - ALPHA ONE, S. Portland, Maine
Robert Van Etten - Rehabilitation Engineer, Rochester, NY
Paul McPhail - South Western Regional Center, Ontario, Canada
Eugene Bianco, Allied Services, Scranton, PA
Mollie Holt, R.N., Seoul, Korea

There were thirty-six people who signed the participants roster during the two symposia, and the energy that was radiated from all of those participants was an important ingredient.

For Immediate Release*

The World Institute on Disability (W.I.D.) and the World Rehabilitation Fund (WRF) are pleased to announce: in conjunction with the 1988 RESNA (ICAART) Conference's Special Interest Group on Volunteer Rehabilitation Technology, a two-part symposium on June 27, 1988 in Montreal, Canada:

"Volunteer Rehabilitation Technology: International Perspectives"
10:30 - 12:00 noon

"Volunteer Rehabilitation: What Works and Why"
4:30 - 6:00 p.m.

The morning Symposium will provide a forum for international leaders in volunteer rehabilitation technology to present information about:

- T.A.D. - Australia
- REMAP - England
- MILBAT - Israel
- Jim Tobias on Volunteer Efforts in the U.S.

including how the programs came into being, how they operate and what drives them.

The afternoon session, using a cross-section of U.S. reactor/discussants will provide a forum for a talk-back session. Applicability to the U.S. of the experiences of the overseas programs will be explored.

Both sessions will be chaired by Jim Tobias.

Plan now to attend what looks to be a very exciting day at RESNA.

For RESNA Information, contact:

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W.R.F. Contact:
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World Rehabilitation Fund, Inc.
400 East 34 Street
New York, NY 10016
tel. #1-212-679-2934

*Flyer distributed prior to conference.

INTERNATIONAL EXCHANGE OF EXPERTS AND INFORMATION IN REHABILITATION

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#14 Childhood Disability in the Family.
Elizabeth Zucman, M.D. France

#15 A National Transport System for Severely Disabled Persons—A Swedish Model
Birger Roos, National Transport Board for the Handicapped, Sweden.

#20 Adapting The Work Place for People with Disabilities: Ideas from Sweden
Gerd Elmfeldt

#21 Rehabilitation in Australia: U.S. Observation.
(Contributions from Several WRF Fellows.)

#23 Methods of Improving Verbal and Psychological Development in Children with Cerebral Palsy in the Soviet Union.
Robert Silverman—Translator.

#24 Language Rehabilitation After Stroke: A Linguistic Model.
Gunther Peuser, Federal Republic of Germany

#25 Societal Provision for the Long-Term Needs of the Mentally and Physically Disabled in Britain and in Sweden Relative to Decision-Making in Newborn Intensive Care Units.
Ernie W.D. Young, U.S. WRF Fellow.

#27 Independent Living and Disability Policy in the Netherlands: Three Models of Residential Care and Independent Living.
Gerben DeJong—U.S. WRF Fellow.

#28 The Future of Work and Disabled Persons: The View from Great Britain.
Paul Cornes, Univeristy of Edinburgh.

#30 Employer Initiatives in the Employment or Re-Employment of People with Disabilities: Views from Abroad, with Introduction by Sheila Akabas

#31 The More We Do Together: Adapting the Environment for Children with Disabilities. (Nordic Committee on Disability)

We regret that several monographs in the series are no longer available, nor can we predict how long the 1979-1984 monographs will be available for distribution.

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K. Garnett, P. Gerber—Editors.

#33 Bridges from School to Working Life for Handicapped Youth: The View from Australia.
Trevor Parmenter—MacQuarie University

#34 Independent Living and Attendant Care in Sweden: A Consumer Perspective.
Adolph Ratzka

#35 Evaluation and Information in the Field of Technical Aids for Disabled Persons: A European Perspective.
A. Pedotti and R. Andrich, Eds. Italy

#36 An International Perspective on Community Services and Rehabilitation for Persons with Chronic Mental Illness
Contributions from the U.K., Canada, Australia and Sweden

#37 Interactive Robotic Aids—One Option for Independent Living: An International Perspective
Contributions from the Netherlands, the U.K. and Canada

#39 Family Supports for Families with a Disabled Member
Contributions from several countries.

#40 New Developments in Worker Rehabilitation—"Workcare" in Australia
Andrew Remenyi, Hal Swerissen, Shane A. Thomas—Editors

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David Vandergoot, Diane Woods—Editors

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